



“Even the way I make my coffee is autistic”:

The lived experiences of autistic women participating in the Icelandic documentary *Seeing the Unseen*

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**MA thesis in Disability Studies
Faculty of Sociology, Anthropology and Folkloristics
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in the Icelandic documentary Seeing the Unseen

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Abstract

This master's thesis in Disability Studies is a qualitative study that focuses on the motivation, impact, and experiences of autistic women in Iceland as self-advocates in the documentary *Seeing the Unseen*. It focuses on the female experience of autism because this tends to be ignored in research as the prevalence of autism is higher in men. The data were gathered through conducting interviews in the period between November 2020 and May 2021. Five of the 17 participants in the documentary took part in this study. Age over 40 years was a selection criterion as the goal was to gain a self-reflective perspective over a long lifespan. This study was informed by hermeneutics as a foundational belief, and Interpretative Phenomenological Analysis (IPA) was used as an approach in data analysis. The most important findings related to the phenomenon of being late-diagnosed autistic women. Improving access to a diagnosis with appropriate services in early life, especially for women, was this study's participants' main motivation for taking part in *Seeing the Unseen*. Empowerment by public disclosure about their diagnosis had a significant impact on their lives. A sense of sisterhood with the other participants was another positive experience of participation in the documentary. A unique aspect in the findings of this study was the participants' explanation of their professional choices and best personality qualities with autism. Another unique aspect was reporting an attraction towards honest, fair and non-mainstream people, who were also possibly autistic. This study intends to provide valuable information for family members, professionals and undiagnosed women who may be autistic.

Ágrip

Ritgerð þessi er til meistaraþráðu í fötlunarfræði og byggir á niðurstöðum eiginlegrar rannsókna á reynslu einhverfra kvenna á Íslandi sem tóku þátt í heimildarmyndinni *Að sjá hið ósýnilega*, þar sem fleiri karlmenn eru greindir með einhverfu en konur og fáar rannsóknir skrifa um reynslu einhverfra kvenna. Tekin voru viðtöl við fimm af 17 þátttakendum í heimiladarmyndinni, sem unnin voru frá nóvember 2020 til maí 2021. Við val á viðmælendum var lögð áhersla á konur yfir fertugu sem geta borið saman skilning sinn á einhverfu miðað við yngri ár. Fræðilegar forsendur rannsóknirnar byggja á túlkunarfræði og notuð var túlkandi fyrirbæralegr nálgun í greiningu gagna. Mikilvægasta niðurstaða úr rannsókninni var að allar konur fengu einhverfugreiningu á fullorðinsárum. Ónógur aðgangur að einhverfugreiningu og viðeigandi þjónustu fyrir einhverft fólk í æsku, sérstaklega fyrir konur, voru aðalástæðan fyrir þátttöku þeirra í heimildarmyndinni. Áhrif heimildarmyndarinnar á líf þeirra var valdefling í formi þess að tjá sig opinberlega um einhverfu. Viðmælendur lýstu því líka að þátttaka í heimildarmyndinni vakti systratilfinningu milli þeirra og hinna einhverfu kvennanna. Sérstaklega athyglisverð var sú niðurstaða að konurnar tengdu starfsval og jákvæða persónueiginleika sína við einhverfu. Þær höfðu líka tilhneigingu til að eiga samskipti við „heiðarlegt“ fólk, sem hugsaði út fyrir kassann og var mögulega einhverft. Vonast er að ritgerðin veiti hjálplegar upplýsingar fyrir fjölskyldur barna með einhverfu, starfsfólk og konur án greiningar.

Foreword

This master's thesis, "Even the way I make my coffee is autistic": The lived experiences of autistic women participating in the Icelandic documentary *Seeing the Unseen*, is equivalent to 30 ECTS – credits in Disability Studies in the School of Social Sciences at the University of Iceland, and was conducted using qualitative research methods. Dr. Snæfríður Þóra Egilson, an Occupational Therapist and Professor of Disability Studies at the University of Iceland, provided invaluable supervision. Her prompt and detailed feedback was always combined with effective encouragement to keep on with the focused work, when I stumbled upon temporary roadblocks. To her responsible and inspiring attitude, I owe my confidence and persistence in finishing this long journey of meticulous writing, analysis, and refining these many thousands of words.

I am indebted to the five interviewees for their courage in speaking openly about the positive and not so positive aspects of living with autism. It was incredibly interesting to listen to and learn from their lived experiences. I am impressed by their self-awareness, wisdom and their wide ranges of interests and talents. I admire their sense of sisterhood with the other autistic women in the documentary.

Furthermore, the happy future of my daughter Yulia was the motivation for this study. My parents and brother have also been my rock-solid source of unconditional love and support.

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1 Introduction

My initial intention was to focus on autistic women and their social challenges in my MA thesis. It was a fortunate coincidence that the documentary *Seeing the Unseen* [Í. Að sjá hið ósýnilega] (Lúðvíksdóttir & Kristjánsson, 2019), was released at the same time as I was deciding my topic. To the best of my knowledge, this Icelandic documentary is the first and only documentary about autistic women in the world where the narrative is not led by non-autistic professionals but by autistic women themselves. In *Seeing the Unseen*, 17 participants of various ages talk about their experiences as autistic women living in Iceland: the search for diagnosis, social exclusion, bullying, relationship abuse, job difficulties, mental health issues, passionate interests and pursuit of dreams. In their understanding, social difficulties appear to be the most challenging aspect of living with autism. In this small qualitative study, I interviewed five of the participants, who were all mature women over the age of 40. Their retrospective accounts provided a wide context for their individual motivations and experiences of participation in this unique documentary.

1.1 Motivation for this study

My occupation as a social educator involves assisting people with special needs, nurturing the individual's strengths and supporting their advocacy for human rights and inclusion. It is my professional responsibility to listen to and learn from autistic people because they are the experts on autism. In my BA thesis in social education, I discussed autism with an emphasis on working with children and their families. This MA thesis in disability studies gave me an opportunity to learn more about autistic women in particular. As a non-autistic person, I was interested to learn how non-autistic people could facilitate meaningful relationships by meeting the needs of autistic people on their terms in everyday interactions. To gather that knowledge, it was imperative to learn from the autistic women themselves. As a parent of an autistic teenage girl, I try not to succumb to worries about her adult future with the complexities of group dynamics, friendships and dating. This study also gave me optimism from knowing that my daughter will find honesty, respect and emotional connection in the autistic community.

1.2 The study at a glance

The aim of this study was to shed light on the meaning-making in the women's experiences of living with autism, as well as to uncover what they perceived as the benefits and negative aspects of participation in the documentary.

The research questions are:

1. What were the autistic women's motivations for participating in the documentary *Seeing the Unseen*?
2. How do the women describe the impact of their participation in the documentary, their key learnings on their sense of belonging as equal members in society and the attitudes of other people toward autistic women?

1.3 Evolution of the autism diagnosis

Autism is not a natural or stable category, but was developed under power structures held by non-autistic professionals as a psychiatric diagnosis, and it has evolved later to a cognitive condition (Evans, 2013). The first diagnostic criteria of infantile autism with an emphasis on aloneness, insistence on sameness, language delay and specific cognitive differences was introduced by the American psychiatrist Kanner in the 1940s, but adult identification did not take place until the 1980s (Lai & Baron-Cohen, 2015).

Kanner's limited definition of autism as a childhood psychopathy became more inclusive in 2013, when the *Diagnostic and Statistical Manual of Mental Disorders (DSM-V)* recognized autism as a spectrum of conditions with common roots (Silberman, 2015). The new definition includes the former diagnostic categories of *autistic disorder*, *high-functioning autism*, *Asperger's syndrome*, and *pervasive developmental disorder not otherwise specified* (Lai & Baron-Cohen, 2015).

Today autism is defined as a neuro-cognitive condition characterized by difficulties with social interactions, reciprocity, flexibility, and processing of sensory stimuli (American Psychiatric Association [APA], 2013). Prevalence of autism is higher in men compared to women with a male-to-female ratio of four-to-one (Fombonne, 2009), and autistic women are under-represented as a minority in autism research (Shefkyck, 2015). The most common stereotypes of autism are still associated with being a white, male, and minimally verbal child (Botha et al., 2020).

The concept of the *autism spectrum* is considered to be a progressive change, because it provides an opportunity for diagnosis and access to support services to many previously excluded people (Silberman, 2015). Adult diagnosis can be still challenging for several reasons: lack of developmental history, the use of *camouflaging* strategies¹, and high rate of co-occurring diagnosis with the risk of potential misdiagnosis (Lai & Baron-Cohen, 2015).

The health care professionals have started using the neutral and less stigmatizing word *condition* in order to be more respectful toward the autistic community, because the word *disorder* implies dysfunction and a need to be cured within the biomedical model² (Lai & Baron-Cohen, 2015). However, a diagnosis is based on the experience of substantial functional impairments, and the wording of autism as a disorder is still required by health care and insurance systems (Lai & Baron-Cohen, 2015). This important trend towards avoiding the term disorder is motivated by acknowledgement of autism not only as a disability, but a neurological difference with strengths and talents (Lai & Baron-Cohen, 2015). Runswick-Cole and colleagues (2016) point out that there is no conclusive evidence of brain difference and genetic origin, and no theory fully explains the nature of autism. In other words, making a diagnosis is based on the assumption of an observable neurological difference, where a display of the same cognitive profile can be an advantage in certain environments and can lead to disability in other environments (Lai & Baron-Cohen, 2015), which is in accordance with the Nordic relational model of disability³ (Tøssebro, 2000).

Public discourse with emphasis on deficits and dysfunction results in societal othering of autistic people, which involves stigma, exclusion, bullying and attempts to force conformity (Milton & Sims, 2015). Many studies support the idea that a diagnosis disclosure leads to a better understanding and acceptance in society, but some autistic

¹ The term *camouflaging*, also known as *masking*, refers to an individual's use of strategies to suppress and control their autistic behavior in an attempt to cope with social challenges by imitating non-autistic behavior. It is physically exhausting and has a damaging effect on mental health for lack of authenticity, and must not be encouraged (Hull et al., 2017).

² *The biomedical model of disability* will be discussed in the next chapter.

³ *The Nordic relational model of disability* will be discussed in the next chapter.

people recommend selective or non-disclosure depending on the context (Thompson-Hodgetts et al., 2020). Autism diagnosis with a desire for public disclosure was a prerequisite for participation in the documentary.

1.4 Importance of this study

This study was informed by identifying relevant Icelandic research and corresponding foreign research as a foundation. Most Icelandic research on autism has focused on prevalence and comorbidities, as well as diagnostic and intervention practices in childhood (Jónsdóttir & Sæmundsen, 2014). I found three studies about the quality of life for autistic children and youth (Egilson et al., 2018), which focused on environmental and contextual factors as well as their home participation (Egilson et al., 2018) and community involvement (Egilson et al., 2017). Only one Icelandic study has explored the interests of Icelandic teenage girls with Asperger's syndrome (Gunnarsdóttir, 2009), which suggested gender differences in autism but provided insufficient information. Another study focused on autism as a different sensory experience, which was also in support of a diagnosis disclosure (Þórhallsdóttir, 2014). In other words, those studies were remotely related to autistic women. There is also not an abundance of foreign literature on the same subject, but some recent research have recognized the importance of distinguishing autism gender differences (Bargiela et al., 2016, Sedgwick et al., 2019; Sedgwick et al., 2018; Tierney et al., 2015).

When I decided on a subject for this study, I was not aware yet that there was a significant difference in the experience of autism to the point, that Lai & Baron-Cohen (2015) defined an existing *female autism phenotype*, and Saxe (2017) proposed that the measures for identifying autism in women should be constructed alongside the official diagnostic criteria. In general, the female experience of autism tends to be ignored as a minority in research, because the prevalence of autism is higher in men (Fombonne, 2009), and the focus in autism research is traditionally on autistic men (Shefyck, 2015). Not only because there are more autistic men than women but because the criteria are still very male-dominated, autistic women tend to be under-diagnosed (Bumiller, 2008; Kirkovski et al., 2013) or mis-diagnosed (Kirkovski et al., 2013).

In this process of reviewing existing literature, I realized the importance of listening to the critical perspectives in the autistic academic community (Bolton, 2018; Guest,

2019; Milton, 2012), because most of my theoretical knowledge was based on non-autistic scholars.

1.5 Theoretical framework

The study is informed by the lens of Critical Disability Studies (CDS). It focuses on an interdisciplinary academic debate with an open-mindedness about disability issues and the consideration of multiple contexts in the lived experiences of disability (Goodley et al., 2019). Critical Autism Studies is a branch of CDS, but it supports the neurodiversity concept as a dominant ideology (Bolton, 2018; Guest, 2019). In the spirit of CDS, I tried to describe opposing voices within the autistic academic community in an unbiased way, and avoided labelling non-autistic people as neurotypical. I found Goodley's concept of *The Dis/ability complex* (2018) to be useful, where he raised the question about the accountability of scholarship, and discussed the binarisation of life where “*ableism and disablism feed off each other*” (Goodley, 2018, p.7). In his opinion, the problem with the global politics of diagnosis was the contradictory division of people in terms of the same and others, but “*a life worth living is a life lived with others*” in a respectful and harmonious interconnectedness (Goodley, 2018, p.14).

1.6 Structural overview

This thesis is divided into seven chapters. The first chapter introduces the subject of autism from a female perspective and the role of a diagnosis. The second chapter explains the role of different disability perspectives and describes the key aspects in autistic self-advocacy, which are: the role of environment, identity language and the neurodiversity concept, as well as a comparison between the directions in Critical Disability Studies and Critical Autism Studies. The third chapter describes old and new autism theories as well as recent research in support of the latter. It aims to explain the autistic and female perspective in social interactions. The fourth chapter explains the methodology used in this study and the way in which it was carried out. The findings are described in the fifth chapter, where the first research question is divided into two subchapters and the second question is answered in the third subchapter. In the sixth chapter, I interpret the summary of the findings in light of previous literature, and I also propose ideas for accommodations. In the last chapter, I highlight the key aspects in the findings.

2 From the perspective of disability studies

Understanding of autism is based on many different perspectives. In the first subchapter, I will explain the influence of the *biomedical*, the *British social* and *Nordic relational models of disability* as fundamental beliefs in disability studies. The impact of the Nordic perspective on understanding of autism will be exemplified by bringing attention to the interplay between environmental and individual factors in the experience of autism as a person-environment relationship. The impact of the British social model on autistic self-advocacy manifests as: challenging the existing social hierarchy by reclaiming the word *autism* from stigmatizing labels, and reframing the connection between autism and *identity*. It explains the motivation of autistic individuals to embrace the *neurodiversity* concept as a more value-neutral perspective of autism compared to the biomedical model, despite lack of evidence for a brain difference. The second subchapter focuses on the similarities and differences between *Critical Disability Studies* and *Critical Autism Studies*, and emphasizes that not every autistic scholar is supporter of the neurodiversity concept as a reason for disputes within CAS.

2.1 Disability models and concepts

The everyday understanding of disability has been heavily influenced by the biomedical perspective with an emphasis on the body with functional limitations, and the cause is solely attributed to the individual's responsibility about their health condition (Tøssebro, 2000). According to this understanding, disability is considered a personal tragedy, and the focus is aimed mostly at prevention and treatment of functional limitations (Tøssebro, 2000). However, disability activists have challenged this individual and medical understanding by introducing the social model of disability: both in the stronger British and weaker Nordic version. According to the social model, disability policy is aimed at changing the man-made factors in producing disability as a consequence of inaccessible and unsupportive environments (Tøssebro, 2000).

The field of disability studies emerged from the political activism and self-advocacy work of the disability equality movement in the 1970s and 1980s (Shakespeare, 2014). The disability scholars from “classic British social model” made a revolutionary distinction between *disability* and *impairment*, because they focused on removal of environmental barriers and changing the social norms producing disability (Shakespeare, 2014). In other

words, disability was considered to be caused by society, which was not adapted to everyone's needs. Thus, people were by definition discriminated and disabled by society (Tøssebro, 2000). In this way, the British social perspective empowered disabled people to demand legal rights and respect as equal members of society, because they were not responsible for the experience of environmental limitations and were not in need to be cured (Shakespeare, 2014). Disability studies have also changed the understanding of autism by emphasizing the role of environmental factors in the individual's experience of autism. The British social perspective rejected the pathologizing of autism as a disease and disorder (Evans, 2013), and focused on changing the negative stereotypes of autism as a bad trait to have and in need to be fixed (Botha et al., 2020).

The British social model has been criticized for neglecting the reality of living with bodily limitations (Tøssebro, 2000). As a disabled person, the British scholar Shakespeare (2014) considers not all environmental limitations to be a sign of oppression, because a barrier-free world is a utopia. He further explains that the disability movement is led by wheelchair users and does not encompass the impairment-specific needs of diverse groups, perhaps based on a fear of reinforcing a hierarchy of disability by examining impairment differences. Furthermore, the removal of physical barriers is not the only environmental factor producing the experience of disability. Interactions between disabled and non-disabled people can also undermine the physical and emotional well-being of a disabled individual (Shakespeare, 2014).

In comparison, the Nordic social perspective acknowledges these criticisms by redefining disability as a mismatch in the relationship between the person's functioning and the environmental demands (Tøssebro, 2000). Today, the relational understanding of disability is at the forefront. For instance, it is reflected in the Preamble (e) of *The UN Convention on the Rights of Persons with Disabilities (UNCRPD)*:

Recognizing that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others (UN, 2006).

2.1.1 The person-environment fit

This section aims to showcase the utility of the Nordic perspective of disability. Icelandic studies explain the tendency of autistic children and youth to engage in solitary activities with excessive computer use, because the communicative, cognitive and physical demands of group activities exceed the individual's capacity for participation (Egilson, Jakobsdóttir et al., 2017; Egilson, Ólafsdóttir et al., 2017). These authors question the taken-for-granted assumptions that the impairments are the only reason for the social exclusion of autistic children and youth, but point at the lack of environmental supports, the role of contexts, discriminatory practices and economic hardships (Egilson, Jakobsdóttir et al., 2017).

Article 2 of the UNCRPD defines the legal right of autistic people on “reasonable accommodation”, which is “necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden” (UN, 2006, p. 4). The social participation of autistic individuals through individualized and effective measures, including peer support, is highlighted in article 26-1 (UN, 2006). Similarly, article 24-3 facilitates the autistic learning of life and social development skills to maximize inclusion (UN, 2006).

The social isolation of autistic people can also be reduced by educating non-autistic people to be supportive of autism (Shakespeare, 2014). Supportive strategies entail anticipating and preventing autistic challenges, as well as setting priorities and structuring routines (Egilson et al., 2018). Accommodating environments are respectful of individuals displaying social non-conformity by enabling their use of autistic talents, such as attention to detail and ability to spot patterns (Lai & Baron-Cohen, 2015). Creating a social life for autistic people is exemplified by inclusion in group activities, which are highly structured such as card games, as well as a public appreciation for the individual's knowledge in the experience of shared interests (Lai & Baron-Cohen, 2015). In comparison, unsupportive environments are highly stressful with demands for excessive communication and multitasking (Lai & Baron-Cohen, 2015). A provision of accommodations also includes a reduction of sensory overload in the environment (Young, 2012).

In brief, autism spectrum conditions might manifest as a disability in inappropriate environments, but could be considered an individual strength in different contexts (Lai & Baron-Cohen, 2015).

2.1.2 Autistic identity as a self-advocacy

Apart from removal of environmental barriers, the British social model focused on language management as a tool of empowerment (Shakespeare, 2014). Public discourse maintains a hierarchy of functioning as a form of controlling minority groups, and autistic people constitute a minority (Botha et al., 2020). Reclaiming language weakens the stigmatizing power of biomedical labels, because stigma causes suffering not autism (Botha et al., 2020).

The British disability activists adopted the wording *disabled people*, or identity-first terminology, because individuals with impairments were disabled by society and not by their body (Shakespeare, 2014). By the same logic, autistic self-advocates support the use of *autistic people* as a base for autistic pride and belonging to the autistic community (Guest, 2019). In comparison, the term *people with disability*, or people-first language, implies a regression to the stigmatizing biomedical model (Shakespeare, 2014). Thus, *people with autism* means that autism is separated from the self as a disease. It also indicates a denial of autistic human rights (Botha et al., 2020). Disabled individuals, who refuse to identify by their impairment, are rejected by the disability community. The accusation is of having a false consciousness and suffering from an internalized oppression (Shakespeare, 2014). Many autistic self-advocates perceive the use of person-first language by non-autistic people as being condescending. They compare those people to the anti-vaccine parents, who take the risk of deadly diseases rather than having an autistic baby (Botha et al., 2020).

But the identity-first terminology is not universally accepted. The refusal to define someone in terms of their impairment is seen as a respect for our shared humanity (Shakespeare, 2014). Outside of UK, the wording people with disability is the dominant terminology in North America and Australia (Shakespeare, 2014). For instance, the *UNCRPD* uses people-first language (UN, 2006).

Some autistic scholars believe that identity-first choice may trap autistic people in a bubble of self-isolation (Guest, 2019). Instead of separatism, the goal of the disability movement is supposed to be promotion of equality and inclusion (Shakespeare, 2014). Others believe that identity must be an individual choice. For instance, the autistic scholar Guest (2019) has never identified herself with her autism diagnosis, because she thinks

of her identity as being much more than a label. At the same time, she has no problem if others choose to identify with their autism. The autistic scholar Bolton (2018) considers himself both autistic and a person with autism, because self-worth does not lie in words but in acceptance of one's condition. He believes that individuals should be free to decide for themselves what choice of language makes them happy, but they must not attack disrespectfully the different preferences of other people. Bolton (2018) expresses a concern about the growing hostility toward different voices, especially of non-autistic professionals and researchers. He thinks that in-fighting and negativity within the autistic community move self-advocacy away from progress.

It is noteworthy that the autistic community encompasses a wide spectrum of individuals with diverse needs: some are nonspeaking, others have intellectual and co-occurring conditions (ASAN, 2017). *The Autistic Self Advocacy Network [ASAN]* has adopted the motto of the disability movement, which is “Nothing about us without us” (ASAN, 2017). It aims to change how society thinks about autism by ending harmful stereotypes (ASAN, 2017). For instance, ASAN discards the labels of *high-functioning* and *low-functioning autism*, because nobody is too disabled to be a self-advocate. *Self-advocacy* simply means taking control of your own life (ASAN, 2017). Some high-functioning autistic individuals dislike the term *autism spectrum* because non-autistic people reject their identity as not autistic enough, and they argue that an identity is either autistic or non-autistic (Botha et al., 2020).

2.1.3 The neurodiversity concept

The difference between autistic self-advocacy and support for neurodiversity is not immediately apparent. Many self-advocates embrace neurodiversity as a different brain wiring, because autism becomes similar to other biological features, such as a different hair color and being left-handed (Botha et al., 2020). In fact, the concept includes any brain-based conditions, such as intellectual, learning and mental health impairments, not just autism. Autistic self-advocates tend to call themselves *neurodiverse*, and people without brain-based conditions as *neurotypical* (ASAN, 2017). Technically, an individual can be both non-autistic and neurodiverse, but they may still exhibit neurotypical prejudice toward autism as an outsider of the autistic community.

The broad umbrella term of neurodiversity causes other misunderstandings. For instance, neurotypical people tend to confuse autism with an antisocial psychiatric diagnosis, and may even associate it with violence, aggression and mass murder⁴. Their confusion may result in discrimination of autistic people (Botha et al., 2020; Holt et al., 2021).

Some autistic individuals believe that people with intellectual impairments get a differential treatment with a display of affection and excitement while the autistic person gets criticism for antisocial behavior, when they both find pleasure in the same solitary and repetitive activity (Holt et al., 2021).

In other words, the neurodiversity concept is supposedly inclusive of any brain conditions, but neurodiverse people don't share a sense of community with other types of brain impairments because they experience an unwritten hierarchy of acceptance and support for different impairment needs in society. According to Shakespeare (2014), this attitude of separatism is not unique to autistic people, because many disabled individuals are reluctant to admit adopting a hierarchy of impairment themselves for fear of implying that some needs are more worthy than others.

ASAN does not seem to support an attitude of separatism. Neurodiversity is their foundational belief, that no two brains are the same and a normal brain does not exist. Society must not get rid of autism, but celebrate human differences by inclusion of minority groups with any brain-based conditions (ASAN, 2017).

Written by non-autistic scholars from Critical Disability Studies (CDS), the book *Rethinking Autism* (Runswick-Cole et al., 2016) dared to challenge the status quo of neurodiversity and provoked a heated debate, criticism and hostility within Critical Autism Studies (CAS). It questioned the legitimacy of having an autism diagnosis, because there is a lack of genetic evidence for a brain difference (Guest, 2019). In other words, the debate about the legitimacy of the autism diagnosis and neurodiversity is approached differently from the broad perspective of CDS and the narrower understanding of CAS.

⁴ Lai & Baron-Cohen (2015) explain the distinction between *cognitive empathy* of individuals with antisocial behavior and *affective empathy* of autistic people in Chapter 5.2.

2.2 Critical Disability (Autism) Studies

Critical Disability Studies emerged as a sophisticated and nuanced interdisciplinary field because contributions of feminist, queer, postcolonial and critical race scholarship lacked representation in the early thinking of disability scholars (Goodley et al., 2019). For instance, feminism introduced the importance of subjective accounts in qualitative research and the concept of *intersectionality* as the individual's experience of multiple disadvantages from many oppressions (Meekosha & Shuttleworth, 2009). In other words, contemporary times require the impact of multiple identities to be taken into consideration in the experience of disability, such as race, ethnicity, gender, sexuality, age and class (Goodley et al., 2019). The feminist scholars also extended the term *disablism* beyond environmental barriers to *psycho-emotional disablism* as relations of oppression (Shakespeare, 2014).

Goodley (2018) defined critical studies of *ableism* as a central development in CDS by pointing out that ability dominates the workplace and educational institutions. It is motivated by consumer and labor dynamics, which rule the capitalist market with an obsession for the individual's autonomy and self-actualization (Goodley, 2018). The main aim of CDS is to stimulate a critique of ableism and the status quo without providing answers. It also tries to abandon binary concepts, such as the terms disability versus impairment (Meekosha & Shuttleworth, 2009). Instead, CDS tries to reframe ability in non-ableist ways, where disability is both a place of oppression and opportunity (Goodley et al., 2019). For instance, disability invites flexibility in the classroom organization and re-engagement of parents in the education of their children (Goodley et al., 2019).

Another aspect in CDS is embracing the importance of public discourse from cultural studies. Traditionally, impairment has been used as a metaphor for various moral statements to enrich the narrative by associating superficial physical attributes with good and bad personality traits. Therefore, the emphasis in cultural studies is on ending the dominant negative stereotypes of disabled people in media representation, such as agents of exotic realism, pitiful helplessness and dependency, as well as the other extreme images of heroic and asexual saints to megalomaniac villains (Taylor, 2008). Positive portrayals focus on disabled individuals in casual situations, where their impairment is just one of many other personality traits (Taylor, 2008). Historically,

disabled people are ignored as misfits and lack center stage roles in society. Without consulting the disabled community, they are oftentimes represented by non-disabled people instead of themselves (Taylor, 2008).

In particular, there has been anger in the autistic community that non-autistic scholars tend to exhibit neurotypical bias by misinterpreting autistic culture (Milton & Sims, 2016). Critical Autism Studies emerged in 2011, when autistic activists and academics criticized CDS for lacking autistic authorship (Woods et al., 2018). In their opinion, the contributions of autistic scholars about the workings of their own minds are deemed an untrustworthy source, because public discourse characterizes autistic people as lacking an ability for understanding mental states in social interactions (Gernsbacher & Yergeau, 2019).

Additionally, many autistic individuals feel discriminated that research topics prioritize autistic behavior from non-autistic perspective. For instance, stimming is considered an inappropriate conduct by non-autistic social norms, but autistic individuals use it as a very helpful strategy in balancing sensory overload. In comparison, the importance of reducing sensory overload in the environment is ignored, which is a deeply disturbing issue for autistic people (Holt et al., 2021).

In general, CAS supports autism as a diagnostic label and seeks emancipation of autistic people as a neurologically different form of life (Woods et al., 2018). The three aspects of critical thinking in CAS seem compatible with the theoretical direction in CDS: 1) challenging the power relationships of oppression in the construction of autism (Davidson & Orsini, 2013), 2) changing the biomedical discourse and the negative stereotypes about autism (Davidson & Orsini, 2013), 3) developing new approaches with emphasis on the highly individual nature of autism (Davidson & Orsini, 2013).

However, some autistic scholars accuse the leadership in CAS of dismissing any autistic and non-autistic voices, who question the neurodiversity's status quo (Bolton, 2018; Guest, 2019). Clearly, there are different voices in CAS, which do not always agree on issues and priorities. For instance, the autistic scholar Bolton (2018) defends those non-autistic scholars who have been the recipients of hostility, because scientific theories are not facts and each theory has a historical worth. He believes that the subjective lived experiences of autistic people cannot deny the objective utility of science. In Bolton's

opinion (2018), conflicting theories can co-exist because they enable progress, but in a spirit of collaboration with a strong sense of open-mindedness between disputing academic counterparts.

3 Changes in autism knowledge

The classic triad of autism theories will be discussed in the first subchapter, which explains the difference between autistic and non-autistic brains: Theory of Mind Deficit, Weak Central Coherence Theory and Executive Dysfunction Theory (Frith, 2003), as well as the additional Theory of the Extreme Male Brain (Baron-Cohen, 2002). The first theory - which was based on laboratory tests and measures within a positivist tradition - has become the most influential construct for understanding the social difficulties of autistic people (Holt et al., 2021). Critical autistic scholars question the methodology and perceive those theories as a reflection of non-autistic biases, because the results are not based on insider perspectives and produce negative stereotypes of autism (Holt et al., 2021).

The autistic scholar Damien Milton proposed the new Double Empathy Theory, which deconstructs the hurtful assumption of autistic people lacking empathy by pointing out that social interactions are a reciprocal exchange. In other words, it should be equally taken into account that non-autistic people also lack understanding and empathy toward autistic counterparts in a failure of communication. Milton's theory is in correspondence with the Nordic relational understanding of disability, where individual and environmental factors play an equal role. Criticism of the classic theories and the merits of Milton's theory will be discussed in the second subchapter. This subchapter also showcases recent studies, which support the Double Empathy Theory by proving that Theory of Mind Deficit is not a universal part of the autistic experience (Holt et al., 2021), but a devaluation of autistic self-determination (Gernsbacher & Yergeau, 2019). Autistic people reclaim a different, autistic kind of empathy (Holt et al., 2021).

The fourth subchapter explains how autistic women navigate social challenges in a different way compared to autistic men and non-autistic women. The fifth subchapter focuses on Icelandic research in relation to the subject matter of autistic women.

3.1 Old theories and stereotypes

Bolton (2018) emphasizes the role of historical context. It is important to remember that Kanner's early definition and interpretation of infantile autism was based on observation of case studies without empirical methods, and no scientific attempt had been made to understand autism before the classic triad of theories emerged in 1985 (Silberman, 2015). Although the autistic community is critical of the deficiency discourse, the triad of

theories should be respected for their pioneering role in advancing scientific knowledge about autism (Bolton, 2018).

The first theory, Theory of Mind Deficit, is based on the existing *Theory of Mind*: the latter explains the unconscious ability of mind reading in early childhood psychology, when non-autistic people learn to attribute intentions, knowledge and feelings to other people and predict states of mind (Frith, 2003). Non-autistic children start to develop this ability, called *mentalizing*, from the age of four onward, when they understand that another person's thoughts and actions are different from one's own (Frith, 2003). In contrast, *Theory of Mind Deficit* is about the inability of autistic individuals to understand the feelings of other people (Frith, 2003). In result of this inability, autistic children do not engage in spontaneous pretend play, which is a basic developmental stage in learning about the environment through experience (Frith, 2003). For the same reason, autistic people don't realize that they say the wrong thing until after somebody else becomes very upset (Frith, 2003). However, autistic adults can replace the intuitive ability of mentalizing by compensatory learning about mental states through rules of logic, although the strenuous effort can fail under time pressure (Frith, 2003).

The second theory is about the Weak Central Coherence of autistic people. *Central coherence* is the brain's tendency to organize large amounts of information: the memory strategy of non-autistic people focuses on large units, and the memory of autistic people is based on small elements (Frith, 2003). The memory processing style of non-autistic people is called a *strong central coherence*, when they generalize memories of random objects and events into broader groups and contexts (Frith, 2003). The positive aspect is an ability to apply the gained knowledge from a certain experience in similar situations. The negative aspect is a limited memory capacity, for example, in remembering abstract passwords (Frith, 2003). In contrast, autistic people have a *weak central coherence*: the positive aspect is a superior ability in noticing the tiniest details and memorizing a long string of unrelated units, but the negative aspect is an inability to recognize the larger context of those details (Frith, 2003). Formal education, for example, enables the acquisition of abstract and critical thinking, which is independent of context and is in favor of weak central coherence (Frith, 2003). Thus, autistic people are described as non-conformists, who tend to be unaffected by others' opinions (Frith, 2003).

The third theory, *Executive Dysfunction Theory*, provides an explanation for the intense interests and stereotypical behavior of autistic individuals, which are a product of atypical brain function in the frontal lobe. It manifests itself in problems with multitasking, control of attention, rigidity of habits and lack of inhibition (Frith, 2003). When their brain is overloaded with too much information, autistic people use repetitive movements in stressful situations as a helpful mechanism to minimize levels of arousal, due to excess dopamine (Frith, 2003). Non-autistic people tend to misunderstand the display of stereotypical behavior as a signal of boredom and inattention, and deem it as socially undesirable (Frith, 2003). Furthermore, intelligent autistic individuals find it deeply frustrating that their inability to make eye contact, speak and control self-stimulatory behavior are also commonly assumed to be a manifestation of cognitive delay (Holt et al., 2021). The non-autistic psychologist Frith (2003) explains that imposed structure from outside leads to improvements of stereotypical behavior over time. However, the autistic scholar Milton (2012) points out that behavioral modification is experienced as imposition of authority and traumatic invasion by autistic individuals.

Autistic people report a sense of feeling trapped by stigma and stereotypes, which are damaging to their identity and lived experiences (Botha et al., 2020). The most common stereotypes of autism are negative as being awkward, difficult and angry, and are less often positive of having a high intelligence and rare abilities (Wood and Freeth, 2016). For instance, the movie *Rain Man* (Johnson and Levison, 1988) has reinforced the myth of autistic people having savant skills in popular culture. The non-autistic journalist Silberman (2015) proposes a hypothesis about autism as the computer geek and engineers' condition, because he reports an exceptionally high demand for autism services in high-tech hot spots like Silicon Valley. He suggests that the reason lies in assortative mating between men and women with similar genetic traits, because the fathers and grandfathers of autistic children were likely to be engineers. In fact, the non-autistic psychologist Baron-Cohen is responsible for the geek myth, when he extended the triad of theories with the introduction of an additional *Theory of Extreme Male Brain* (Baron-Cohen, 2002). Autism is explained with an excessive exposure of prenatal testosterone, which changes how the brain develops (Morgan, 2015). The information-processing style in the brain of autistic individuals, called *systemizing*, involves an intuitive

understanding of how mechanical objects work with a preference for the physical world instead of psychological states (Frith, 2003).

The autistic scholar Bolton (2018) points out that this theory is particularly offensive to those autistic people who identify themselves as neither male nor female. Similarly, many autistic women protest against the assumption that they are male-brained, and accuse this theory of shifting attention away from the needs of autistic women (Jack, 2012). The autistic scholar Milton (2014) comments that the extreme male brain is a crude reference to autism in scientific literature, which neglects the specific expertise of the autistic community and produces the simplistic machine-like myth of autistic people in popular understanding.

3.2 The double empathy problem

Milton (2012) raises questions about the validity of the above-mentioned classic theories, where autism is presented as a brain dysfunction. Those theories have reinforced the harmful stereotype of autistic people lacking empathy, who are also assumed to be responsible for their social difficulties (Gernsbacher & Yergeau, 2019). The stereotype of being an uncaring, self-centered and antisocial individual is particularly discriminatory toward autistic people, who work in the care-taking professions. They report being kind, polite and loving people, but their intense responsivity to other people's suffering is not recognized because autistic people are not expected to be empathic (Holt et al., 2021).

Gernsbacher & Frymire (2019) criticize the methodology of the experiments, which serve as a foundation in the triad of theories. For instance, the language problems of autistic children are not taken into account in the interpretation of data. Guest (2019) offers an alternative explanation for the results in relation to the Theory of Mind Deficit, that autistic children perform differently compared to non-autistic peers because they do not understand why people lie. She proposes to rename it as a Theory of Deception. Guest (2019) asks rhetorically whether society would become more accommodating of autism if non-autistic people learned to be more honest toward themselves and others. Frith (2003) admits that the ability of mentalizing has a negative consequence when non-autistic people try to deceive others on purpose, so the autistic difficulty with mentalizing is not a bad trait to have.

Lai & Baron-Cohen (2015) provide a new explanation for the confusion in these early theories: by making a distinction between *cognitive* and *affective empathy*. Autistic people face difficulties in cognitive empathy, because their brain doesn't read information about emotions from the expressions of other people (Lai & Baron-Cohen, 2015). When social expectations of an appropriate behavioral response are not met, non-autistic people assume a lack of affective empathy but autistic people do exhibit affective empathy. For instance, they become upset and want to help when information is provided of another person's suffering (Lai & Baron-Cohen, 2015). In contrast, individuals with antisocial behavior exhibit reduced capacity for affective empathy and are simply indifferent, but their cognitive empathy is intact and they are capable of deception (Lai & Baron-Cohen, 2015).

Regardless of this explanation, the fact remains that autistic people are expected to understand and fit into the non-autistic norms of social interactions (Milton, 2012). At the same time, the non-autistic majority makes no effort to meet the needs of autistic culture. Milton (2012) calls it *the double empathy problem*, because the fault for failure in communication is not one-sided. Milton & Sims (2016) write about the challenges to form meaningful relationships between autistic and non-autistic people. Non-autistic people often marginalize the autistic minority, which results in mistreatment, bullying and exclusion. Receiving diagnosis often increases understanding from others, but the need to pathologize one's identity as autistic to gain acceptance has a negative impact on developing rapport (Milton & Sims, 2016). The practice of hiding one's autistic behavior in a camouflaging attempt to pass as non-autistic is valued by psychologists as a highly adaptive response, but it is at the expense of self-acceptance because conformity is inherently disabling (Milton & Sims, 2016).

Over the last decade, critical autistic scholars have raised the important issue of inclusive research, which is led by autistic stakeholders in order to avoid non-autistic negative biases (Cascio et al., 2020; Chown et al., 2017; Parsons et al., 2020). Here, four recent studies will be discussed in support of Milton's Double Empathy Theory (2012) to showcase the importance of insider's perspective.

The quantitative study by DeBrander et al. (2019) included 32 non-autistic and 32 autistic adults, who viewed brief videos of 40 unfamiliar people (20 non-autistic and 20

autistic strangers). They rated each person in the video on six traits, as well as their interest in future interactions. The purpose was to compare the first impressions and social motivation of autistic and non-autistic raters. Both groups displayed negative first impressions of autistic people by judging them as more awkward and less attractive, which means that autistic people have internalized the non-autistic social norms. Although their impressions improved after the individual's diagnosis was disclosed, non-autistic raters still expressed a lesser desire for future contact, whereas the autistic raters expressed a higher social motivation (DeBrander et al., 2019).

Another quantitative study by Morrison et al. (2019) examined the social context in interactions between 67 autistic and 58 non-autistic participants. In terms of interaction quality, autistic people were not judged as less intelligent and less trustworthy by both groups (Morrison et al., 2019). In terms of partner compatibility, autistic raters placed more value on similar interests and experiences instead of attractiveness. They also tended to disclose more personal information to other autistic individuals. The authors suggested that autistic social motivation was not an individual but a relational outcome depending on the person-environment fit (Morrison et al., 2019).

A between-groups experimental study by Crompton, Ropar et al. (2020) divided 72 volunteers into chains of autistic, non-autistic and mixed sets. A story was read to the first individual in the chain, who recounted the narrative to the next person in line. Then, each participant rated the rapport with their neighbors. The goal was to evaluate the effectiveness of peer-to-peer information transfer, and it turned out that the quality in mixed sets was significantly poorer. The authors suggested that non-autistic participants oversimplified information due to anxiety in reading autistic states of mind, which had a drastic negative impact on the amount of information in their daily communication (Crompton, Ropar et al., 2020).

In the qualitative research by Crompton, Hallett et al. (2020), 12 autistic adults, ten of whom were female, completed semi-structured interviews about their feelings during and after spending time together with other people. All participants reported that their interactions in autistic spaces were effortless and provided mutual understanding. In general, non-autistic people did not take into account autistic needs and preferences, which caused much discomfort and frustration. Consequently, social activities were often

inaccessible due to environmental limitations (Crompton, Hallett et al., 2020). On the other hand, the help of non-autistic friends was invaluable in explaining group dynamics and the wider context of events. In other words, meaningful two-way relationships with non-autistic people were possible despite differences of communication style and being a rarity (Crompton, Hallett et al., 2020).

3.3 Autism gender research

Gender issues have been raised throughout the years, but not much attention has been directed to autistic women in particular (Shefycyk, 2015). As it was previously stated, there are fewer women with autism diagnosis (Bumiller, 2008; Fombonne, 2009; Kirkovski et al., 2013). Female autistic behavior tends to go unnoticed for three main reasons (Shefycyk, 2015).

On one hand, the diagnostic criteria is considered to be male-centered (Lai & Baron-Cohen, 2015; Saxe, 2017), because the male-to-female ratio is four-to-one or higher (Fombonne, 2009) and, as a result, focus in research is also male-centric (Shefycyk, 2015). On the other hand, there are societal expectations for gender behavioral differences and traditional roles (Bargiela et al., 2016, Saxe, 2017). As a consequence, autistic women tend to internalize their social problems such as experiences of depression and anxiety, whereas autistic men externalize them such as a display of hyperactivity and misconduct (May et al., 2012; Oswald et al., 2016). Because of societal expectations, autistic women are under a bigger pressure to use camouflaging strategies and they tend to do it more successfully compared to autistic men (Lai et al., 2018). Thereby, autistic women are often underdiagnosed (Bumiller, 2008; Kirkovski et al., 2013) or mis-diagnosed (Kirkovski et al., 2013).

Another potential reason for receiving a late diagnosis is the high frequency of co-occurring medical and psychiatric diagnoses (Lai & Baron-Cohen, 2015). Typical implications of being late-diagnosed are: a deterioration of mental health in more than 50% of autistic adults (Lai & Baron-Cohen, 2015), and a disproportionately high incidence of experiencing abuse by autistic women compared to other population groups (Bargiela et al., 2016).

Having an autism diagnosis in early life helps the women to understand why they feel different from others by enhancing their self-confidence about one's unique identity and alleviating the pain of exclusion and mistreatment (Ryan & Räisänen, 2008).

3.3.1 Male-centric diagnostic criteria and gender norms

Saxe (2017) addresses the main female autistic issues from a feminist perspective on disability. Based on many academic sources, she provides a list for identifying autism in women, proposing that it should be constructed alongside the official diagnostic male-centric criteria. For instance, Saxe (2017) points out that stereotypical behavior is a main diagnostic feature in the official criteria. However, studies show that autistic women exhibit much less repetitive behavior compared to autistic men (Hartley & Sikora, 2009; Mandy et al., 2012). In contrast, a typical indication of female autism is having more advanced fine motor skills than autistic men (Mandy et al., 2012). The downside of being autistic for women compared to men is experiencing a higher frequency of sensory discomfort (Lai et al., 2011) and attention difficulties (Holtman et al., 2007), as well as struggling with worse sleep issues (Hartley & Sikora, 2009) and more frequent mental health problems (Hartley & Sikora, 2009). As already mentioned, they oftentimes internalize, while autistic men externalize, their social problems (May et al., 2012; Oswald et al., 2016).

A study by Bargiela and colleagues (2016) used mixed methods to gather information from 14 autistic women about their experiences of being late-diagnosed. Their self-reports indicated two big female autistic issues, which were a lack of autism awareness by professionals and the negative impact of gender norms in misinterpreting their autistic behavior. For instance, the women reported that their quiet, passive and compliant behavior was seen by teachers as typical for girls. Their autistic needs had been unnoticed for too long, because the girls trying too hard to be good but they suffered from regular meltdowns at home (Bargiela et al., 2016). In college, high academic and social demands created bigger problems. Their autistic communicative errors were misinterpreted as being rude and lazy, and the autistic girls were often blamed for being bullied and reprimanded for not acting normal (Bargiela et al., 2016).

In writing about late-diagnosed autistic adults, Lai & Baron-Cohen (2015) suggest that health professionals are reluctant to diagnose a woman because of outdated autistic

myths which associate autism with severe communication problems and savant skills. This is why the social struggles of those autistic women are ignored, who may have enough social skills to maintain eye contact and small talk, and are perhaps married with children. Additionally, the authors propose behavioral indicators that a woman is potentially autistic, such as: she is either excessively shy or bossy, forms clingy and overcontrolling attachments to certain people, demonstrates perfectionistic standards and extreme loyalty in friendships, and displays a tendency to speak loudly about taboos.

Lai & Baron-Cohen (2015) point out that young autistic girls also engage in imaginative play but it is scripted and non-reciprocal compared to their non-autistic peers. Further, they describe the restricted interests of autistic girls involving people and animals, whereas autistic boys engage in interests involving objects and activities. Similarly, the study by Bargiela et al. (2016) explains that the restricted interests of autistic people serve as a protection of their self-esteem and provide a sense of achievement and well-being, because their social difficulties often result in having a low self-esteem and inability to say “no” in risky situations.

Specifically, the authors described a tendency of autistic girls and women to please people and avoid conflict at all costs in order to gain validation and acceptance. The negative impact was becoming an easy target for exploitation and ridicule. In interactions with non-autistic women, they felt intimidated because other women often brought vulnerable individuals down. For instance, the subtle remarks of non-autistic women were harder to read between the lines whether the intention was being authentically friendly or sarcastic. In contrast, the autistic women claimed that society allowed men to be more straightforward, which was not an issue of biological differences but gender norms (Bargiela et al., 2016).

Nevertheless, learning to be assertive was an important issue of physical and emotional safety in interactions with non-autistic men (Bargiela et al., 2016). In dating, autistic women had a difficulty in understanding if a man was being just friendly or was attracted to them. The danger of social mimicry was their tendency to copy automatically a man’s flirtatious attempts without realizing it, and many of the 14 women reported being raped by strangers (Bargiela et al., 2016). In relationships, autistic women often felt trapped in unhealthy situations by a perceived obligation as a girlfriend to have sex, even

if they wanted to refuse. Acting over-assertive was the other extreme of their social vulnerability, when being too blunt abruptly resulted in permanently damaged relationships. The authors concluded that counselling was needed to provide social skills, especially as a safety issue (Bargiela et al., 2016).

A few of the 14 autistic women rejected the validity of gender stereotypes refusing to fulfill the traditional nurturing roles of women as girlfriends, wives, and mothers. They reported experiencing a conflict between their autistic and feminine identities, especially those autistic individuals who do not identify by their assigned-by-birth gender (Bargiela et al., 2016). Based on autobiographical accounts, Davidson (2007) wrote about the alienation in the writings of autistic women. She claimed that autistic women often suffered from a dual disconnection from autistic men and non-autistic women.

The academic views are discrepant whether autism or gender plays a bigger role in the experience of close relationships, which will be discussed later in this chapter. Moreover, different authors disagree whether autistic women display superior camouflaging strategies compared to men or not. As explained earlier, the term camouflaging means the individual's use of strategies to control their autistic behavior in order to fit in the societal expectations for non-autistic behavior (Hull, et al., 2017). In the next section, those strategies will be explained in detail.

3.3.2 Superior camouflaging strategies

Lai et al. (2018) observed sex/gender differences in a neuroimaging study of gender differences in autistic social functioning, where 119 adults participated: 33 non-autistic and 29 autistic men, and 29 non-autistic and 28 autistic women. The authors suggested that the autistic female self-reflection was more important than mentalizing in autistic men because the former demonstrated a substantial insight about the impact of their autistic and camouflaging behavior in different contexts. Basically, the findings confirmed shallow and inflexible strategies in men, for example following behavioral rules in a rigid manner without being sensitive to context. In comparison, the camouflaging strategies of autistic women were deep, sophisticated and adaptable.

Another qualitative study by Hull et al. (2017) about the nature, motivations and consequences of camouflaging reported an equal number of autistic men and women

using camouflaging. The participants were 92 autistic adults of 15 nationalities, and a high proportion identified as female and non-binary. Although the study was not directly designed to test the gender disparity in camouflaging, the findings showed no consistent difference in behavioral patterns between genders (Hull et al., 2017).

Autistic people report learning camouflaging strategies in many ways. For instance, they copy non-autistic behavior by direct observation from the person next to them (Tierney et al., 2015), or from watching films (Hull et al., 2017). In addition, many autistic people develop a mental list of appropriate facial expressions and body language in different contexts, because the autistic inability to read non-verbal signals tends to be misinterpreted as indifference and arrogance by non-autistic peers (Hull et al., 2017). Typically, wearing an excessively happy smile is a form of hiding anxious and unhappy feelings in mixed interactions (Tierney et al., 2015). Another example includes the facial display of exaggerated interest in non-autistic conversations (Hull et al., 2017). Some autistic people prepare topics for small talk and anecdotes with potential responses ahead of time. Making a list of unwritten social rules can also be helpful. The easiest strategy is to talk very little and exit the interactions quickly (Hull et al., 2017).

In general, camouflaging is only seen as necessary at the initial stages of forming friendships, because the individual feels more comfortable to show their autistic characteristics after a close connection is already established (Hull et al., 2017). Imitation strategies can be so effective, that other people are surprised to learn that a familiar autistic person hides their true feelings (Tierney et al., 2015). According to Hull et al. (2017), autistic individuals report feeling bad that their close relationships seem fake without a display of authenticity.

The authors warn parents and professionals that camouflaging should not be encouraged because intensive self-monitoring and constant awareness of others' reactions are extremely physically and mentally draining. This is why camouflaging increases the risk of mental health problems (Hull et al., 2017). Notwithstanding, a Canadian review by Thompson-Hodgetts et al. (2020) about the outcomes of autism diagnosis disclosure reveals discrepant viewpoints. The authors recognize a lack of direct observation to evaluate whether diagnosis disclosure leads to positive and long-term behavioral changes in non-autistic people, because disclosure itself is not an instruction

on how to support an autistic person. They point out that some autistic people advocate non-disclosure or selective disclosure depending on the context. Even when their autism diagnosis is accepted, those individuals do not want to be treated differently for fear that their diagnosis will become their main public image (Thompson-Hodgetts et al., 2020).

3.3.3 Gender relational differences

In this section, three foreign studies focus on the social motivation and skills of autistic women in comparison with autistic men and non-autistic women. The findings from the first two studies indicate that the friendships of autistic women are much like those of non-autistic women in terms of emotional sharing (Sedgewick et al., 2018; Sedgewick et al., 2019). Their conclusion contradicts Baron-Cohen's theory of the Extreme Male Brain (2002), where the latter suggested that autistic women experience similar relationships to autistic men. In contrast, the third study by Tierney and colleagues (2015) supports Baron-Cohen's theory that autistic women find female environments to be impenetrable in terms of emotional complexities and indirect style of communication, whereas understanding men is effortless.

The first mixed-methods study by Sedgewick et al. (2018) examined gender differences in adolescent autistic and non-autistic friendships in terms of social networks and conflict resolution. The 102 participants were aged 11 to 18, including 27 autistic and 26 non-autistic girls, and 26 autistic and 23 non-autistic boys. As a key gender difference, the findings revealed that non-autistic women had a wider network of best friends, less-close friends and other not-so-close friends compared to their male peers. In comparison with non-autistic women, autistic women focused on fewer friendships because a small number of friends was simply easier to manage (Sedgewick et al., 2018).

Non-autistic women also showed a tendency to compete with their female friends academically and socially, which often involved relational aggressions such as gossiping and mocking comments. Consequently, the biggest social challenge for autistic women was being unaware of competitive group dynamics. That was why autistic women reported having persistent insecurities whether their friendships were reciprocal. Additionally, autistic women described a high social anxiety for fear of provoking misunderstandings and conflict situations unconsciously (Sedgewick et al., 2018).

Most often than not the autistic female participants talked about having a single best friend as the center of their social life (Sedgewick et al., 2018). This friend often felt pressured for closeness and disengaged from having intense interactions. Another relational problem was the potential of being left behind, when the autistic woman failed to access the social circle of her friend.

In terms of conflict resolution, non-autistic women reported resolving issues by a joint problem-solving, whereas autistic women responded differently in an all-or-nothing approach. The latter oftentimes assumed the entire fault with a quick apology, or ended the friendship as being a hopeless situation (Sedgewick et al., 2018). In comparison with female peers, autistic and non-autistic boys reported similar experiences of having relaxed relationships with male friends, claiming that they never argued. Instead of emotional sharing, they valued activities-based interests and practical support in forming friendships (Sedgewick et al., 2018).

The second mixed-methods study by Sedgewick et al. (2019) compared the retrospective accounts of autistic and non-autistic adult women in their experiences of friendships and romantic relationships. A total of 38 women participated, who were aged between 20 and 40. Half of them were autistic and the other half were non-autistic. Both groups defined emotional reciprocity as the key component of female friendships. Oftentimes, both groups experienced difficult social situations, but autistic women reported being more upset by failure to navigate friendships and their consequential dissolution. Young autistic women also reported a greater vulnerability to exploitation than non-autistic women. However, the former grew more socially confident and satisfied in adulthood (Sedgewick et al., 2019).

The quality and length of romantic relationships turned out to be similar for both autistic and non-autistic women, but their relational approach was quite different. The difference was that many autistic women reported not being into casual dating, and displayed a desire for overcommitment from the start of their partnership. At average, autistic women reported having one or two serious relationship in their lifetime. Instead of having to build her own social network, the partner conveniently provided an access to his circle of friends. That was why autistic women described an intense fear of breakups and loneliness, which motivated their higher tolerance for unacceptable behavior from

partners and staying in unhealthy relationships for too long compared to non-autistic women. Instead of focusing on romantic partners, some autistic women claimed to be perfectly content with having only friends (Sedgewick et al., 2019).

The third qualitative study by Tierney et al. (2015) gathered information from ten adolescent female participants with autism diagnosis about their experiences and strategies in managing school interactions. In their stories, the transitional period of adolescence commonly led to new interests of peers in fashion, dating, and sexual identities. Autistic girls contributed gendered norms as a key source of suffering in their failure to fit in non-autistic female environments, leading them to feel not girly enough. Peer pressure for forming group affiliations increased the visibility of their autistic social exclusion. In result, some of the autistic girls developed mental health difficulties from repeated rejection. They described their unsupportive school environment as predatory, physically assaultive and traumatic.

The autistic girls also conveyed a great desire to form friendships, but finding them was not easy. They oftentimes needed help from their mothers in choosing and maintaining supportive friendships. The participants displayed a strong motivation to blend in with their non-autistic peers, developing sophisticated and detailed strategies in peer-imitation. Tierney et al. (2015) suggested the need for gender-sensitive and developmentally-appropriate supports for autistic girls, because those imitation strategies were more unhelpful than helpful.

3.4 Relevant Icelandic research

As aforementioned, most Icelandic research on autism have focused on prevalence, comorbidities and childhood (Jónsdóttir & Sæmundsen, 2014).

A large-scale and quantitative study by Egilson, Ólafsdóttir and colleagues (2017) focused on the quality of life of autistic children and youth from the perspectives of parents and their children. Reports by 96 autistic children, 211 controls and their parents were evaluated in the domains of physical and emotional wellbeing, autonomy, social support, and the environment. In general, parents of autistic children evaluated their quality of life lower in all domains compared to parents of controls. Autistic children and their parents agreed on their lower ratings in two dimensions, which were social support and physical wellbeing (Egilson, Ólafsdóttir et al., 2017). It is noteworthy that autistic

children rated their quality of life better in four domains, including their psychological well-being, compared to their parents (Egilson, Ólafsdóttir et al., 2017).

A second large-scale and mixed-methods study by Egilson and colleagues (2018) included information about parent's perspectives on home participation of their autistic children. Parents of altogether 99 autistic and 241 non-autistic children responded to a survey about: (1) participation of children with and without autism spectrum disorder in activities at home, (2) the environmental features and resources that affect these children's home participation, and (3) the strategies parents use to help their children participate at home. Parents in both groups used similar strategies to facilitate their children's participation at home, but parents of autistic children made use of more distinct modifications, such as by giving simplified instructions, using visual timetables and reward systems, preparing the child for expected changes and alternative situations in advance (Egilson et al., 2018).

Egilson, Jakobsdóttir et al. (2017) also examined community participation of autistic children using the same sample and questionnaire. According to their parents, autistic children participated less frequently, were less involved, and their parents were less satisfied with their child's participation in community based activities compared with the control group. Parents of autistic children also identified fewer supports for their child's participation and more environmental barriers than other parents. The environmental factors that parents of autistic children most often considered as either not supporting or directly hindering their child's participation included the social, cognitive and physical demands of activities, as well as relations with peers (Egilson, Jakobsdóttir et al., 2017).

Initially a MA-thesis in Disability Studies and later published as a book, a qualitative study by Þórhallsdóttir (2014) focused on autism as a sensory experience in the accounts of five autistic men and three autistic women. The book provided a wealth of information about autism, but not specifically about autistic women. The author wrote that the interviewees had no doubts about the correctness of their diagnosis and considered it beneficial for two reasons. Firstly, it provided an emotional relief and explanation for feeling different. Secondly, it increased understanding by non-autistic people, which improved their social functioning and minimized the experiences of bullying (Þórhallsdóttir, 2014).

The small-scale qualitative study and MA thesis in Disability Studies by Gunnarsdóttir (2009) focused on Icelandic teenage girls with Asperger's condition and their interests. Interviews were conducted with six girls and their mothers. Preoccupation with hobbies and computers served as a compensation strategy for their social difficulties in face-to-face interactions (Gunnarsdóttir, 2009). When being emotionally overwhelmed, the girls also displayed a tendency to speak in English instead of their native Icelandic. The author explained that the use of foreign language was a strategy in establishing a sense of detachment, which was also symbolic of their status as outcasts in society. Further, the author described the six interviewees as tomboys, who preferred male company and were not interested in fashion and domestic chores. The mothers were worried about the social isolation of their girls, playing an active role in helping them with finding friends (Gunnarsdóttir, 2009).

4 Methodology

In writing this chapter, I used the guidelines about qualitative research design by Creswell and Poth (2018). In the first subchapter, I restate the aim of this study and research questions. Next, I articulate the philosophical theory of hermeneutics as a direction for this study. The suitability of Interpretative Phenomenological Analysis as an approach is explained in the third subchapter. The fourth subchapter describes the selection criteria and characteristics of the five interviewees, as well as the recruitment process. The fifth subchapter explains the adaptation of methodological approaches in qualitative research to autistic participants. Then the process of data analysis is described. In the seventh subchapter, the main ethical principles are outlined in accordance with the framework provided by the University of Iceland. In the eighth and final subchapter, my preconceptions about autism are bracketed to diminish my pre-existing assumptions as a researcher.

4.1 Research objectives

The objective of this study was to gain insights into the meaning-making in the participants' female experiences of living with autism, as well as to uncover their perceived positive and negative aspects of participation in the documentary.

The study sought to answer the following research questions:

1. What were the autistic women's motivations for participating in the documentary *Seeing the Unseen*?
2. How do the women describe the impact of their participation in the documentary, their key learnings on their sense of belonging as equal members in society, and the attitudes of other people toward autistic women?

4.2 Philosophical assumptions

Researchers use a framework of philosophical assumptions to provide a direction for the study, such as their view of reality (ontology), how they know reality (epistemology), their values (axiology) and procedures used (methodology). In brief, those interpretative frameworks, or philosophical assumptions, are the beliefs of the researcher that influence the process of qualitative research (Creswell & Poth, 2018). In this study, hermeneutics is the foundational belief as a direction in the qualitative research process.

Hermeneutics is both a philosophical framework and an interpretative methodology, that tries to understand the depth of human day-to-day experience in various contexts (VanLeeuwen et al., 2017). The contemplative engagement of the researcher with texts encourages a reevaluation of traditional understandings by potentially altering existing concepts (Spence, 2017). In other words, working with texts requires a difficult balance between familiarity and novelty (Gadamer, 1996). The goal is not to provide solutions in practical situations, but to reflect on the meaning of existence through the role of language, conversation and ambiguity (Gadamer, 1976; Guo, 2010; Kinsella, 2006).

Spence (1999) explains that the origin of prejudice is in the past, which helps us to make sense of a life experience and its influence on future situations. Further, Spence (1999) defines *true prejudice* as enabling understanding, and *false prejudice* as hindering it. VanLeeuwen and colleagues (2017) write about the researcher as a cultural insider and a cultural outsider. A *cultural insider* understands subtle power relationships and uses culturally responsive strategies in recruiting participants (VanLeeuwen et al., 2017). A *cultural outsider* needs to articulate pre-understandings of local differences in an unfamiliar cultural context around sensitive issues of power dynamics and gender (VanLeeuwen et al., 2017).

Spence (2017) encourages researchers to disclose their feelings, taken-for-granted assumptions, and concerns about the subject by asking how they became interested in it and what experience motivated them. In hermeneutic writing, Spence (2017) warns against the use of absolute truths and strong biases. She recommends words suggesting possibility of interpretation, such as “perhaps,” “seem,” and “may,” as well as words conveying the contradictory nature of the studied subject, such as “but,” “although,” and “at the same time.” The process of interpretation involves meditative questions rather than calculative answers (Spence, 2017). Conflict is an inevitable form of gaining multiple perspectives and a new self-understanding (Lampert, 1997). Hermeneutic writing is never perfect, because interpretation is not beyond challenges (Moules et al., 2015).

4.3 Research approaches

After identifying the philosophical assumptions, the next stage is to adopt a specific research approach to the qualitative study, which entails a description of why it is used and how it informs the study (Creswell & Poth, 2018). I found *Interpretative*

Phenomenological Analysis (IPA) to be a suitable approach for this study, which focuses on the unique experience of individuals. IPA is influenced by the theoretical knowledge both in the hermeneutical and phenomenological traditions (Shaw, 2010). The phenomenological aspect of IPA is the focus on individual experiences, where the interviewee is in a self-reflective role (Braun & Clarke, 2013). IPA also recognizes the role of the researcher's own interpretation, as well as the researcher's critical stance of the participant's self-interpretation. In other words, the study involves a dual process of interpretation, which is called a *double hermeneutics* (Braun & Clarke, 2013).

I used the framework by Shaw (2010) in following the stages of the IPA approach. The most common form of data collection is a semi-structured, face-to-face, in-depth interview, where the interview frame is guided by a flexible order and wording (Shaw, 2010). When the interview analysis with the first participant is complete, the researcher moves to the next person in the sample (Shaw, 2010). IPA research is a data-driven or bottom-up approach, where interpretations are made based on the data and not on existing theory (Shaw, 2010).

Shaw (2010) recommends starting with *descriptive summaries*, where the researcher highlights what the interviewee talks about. These summaries are accompanied by notes about interpretative and conceptual ideas. Shaw (2010) also recommends the use of a *reflective diary*, where the researcher keeps the initial descriptive commentaries and uses them as building blocks when writing *interpretative commentaries* in the later stages of analysis. The diary provides a proof that all claims of interpretations can be evidenced in raw data, and it serves as an interrelationship between early and final stages of analysis (Shaw, 2010). The purpose of the diary is to reflect on the descriptive summaries and identify potential issues, misunderstandings, and contradictions (Shaw, 2010).

The codes are more like broad comments rather than traditional brief codes with key words (Braun & Clarke, 2013). Braun & Clarke (2013) recommend the use of *index cards* with a text extract and location for each code. They also emphasize inclusivity in the early stage of analysis: If the researcher is unsure about the relevance of a code to the research question, it is better to code it and discard it later. This advice was very practical for my study because it provided a wide context for interviewee's replies to the research questions. In the hermeneutical tradition, the context of each woman's entire life was a

tool to enhance my understanding as a researcher in the interpretation of the individual's meaning-making about their participation in the documentary. In subchapter 4.6, I will explain further the IPA process of using Shaw's framework (2010) in data analysis.

4.4 Recruitment and description of participants

Homogeneous samples are typical in the IPA approach (Braun & Clarke, 2013). The 17 Icelandic autistic women in the documentary were of different ages because the moviemakers tried to showcase the challenges of being an autistic woman at any stage of life. I decided to focus on mature women over the age of 40, so they could reflect on their life: how it was different today by comparison with their younger years. Thus, mature age was a selective criterion in this study, where the participants were to engage in a retrospective reflection of their lived experiences as autistic women. Furthermore, the five women got their autism diagnoses late in life, although it was not a conscious selection criterion. All women had completed various educational degrees in a wide range of professional fields, which was also not an intended selection criterion. Despite their average high educational level, their employment situation varied. Most of them were only partially employed. Their family situations differed, too, from having a partner and children to living alone. One participant identified as a queer woman.

I contacted by email the Icelandic autistic organization *Einhverfusamtökin* as a gatekeeper asking them for assistance to get in touch with those women who might be interested in participating in this study. I also emailed the organization a letter of intent about conducting this study (see *Appendix A*). To those candidates who confirmed a desire to take part in the study, I emailed a letter of introduction and informed consent to be signed prior to taking the interview. This form contains information about their ethical rights as participants and my responsibility as a researcher (see *Appendix B*).

4.5 Collection of data

The interviews were conducted from November 2020 to May 2021. In general, it is ideal to take the interviews in person and in the natural settings of the participant (Braun & Clarke, 2013), but the spread of COVID-19 forced rules of social distancing. I decided to give the participants an option to decide for themselves; whether to meet in person with masks or on Zoom. I hesitated to insist on meeting in person, but I decided that

consideration for the convenience of autistic participants was more important than following the rules of qualitative research in a rigid manner. A key aspect of participatory research is inclusiveness by adapting the research environment and methodology to enhance the most accessible and quality engagement of the autistic participants (Fletcher-Watson et al., 2018). According to Parsons et al. (2019), autistic people experience more control over interactions and reduction of anxiety via computers because social norms are more stable than face-to-face communication.

All five of them preferred to use Zoom. One woman experienced technical problems with Zoom and consequently decided to meet me in person at my home instead. Each interview lasted a minimum of 60 minutes. The video interviews were automatically recorded in Zoom, and I downloaded the files on my laptop. I recorded the interview with the one participant, whom I met in person, on my tablet.

My preparation for the interviews consisted of watching the documentary multiple times. I took detailed word-by-word notes for the entire duration of the documentary, so I could get to know each woman as an individual prior to the interview. I also prepared an interview frame with a list of questions for myself prior to conducting the interviews (see *Appendix C*).

I followed the guidelines by Rasmussen & Pagsberg (2019) for customizing the methodological approaches in qualitative research for autistic individuals, which emphasized a strong need for predictability and preparing the interviews by making agreements in advance. That is why I decided to email the interview frame to all participants prior to conducting the interviews. I warned them that the interview frame was not set in stone but served as a flexible guideline. I thought that their familiarization with the interview frame was a good way to establish rapport and minimize anxiety in revealing personal information to the researcher as a stranger. I was initially hesitant about whether familiarization with the questions would produce less spontaneous answers in the interview, but this worry turned out to be unfounded.

Braun & Clarke (2013) recommend the use of open-ended questions in interviews because they stimulate the participants to provide detailed responses instead of answering yes and no to closed questions. However, Rasmussen & Pagsberg (2019) explain that a combined approach works best with autistic interviewees by beginning

with close-ended questions and then adding open-ended questions. Opening up the interview with simple, precise, and structured questions is advantageous because the autistic individual might experience difficulties with discussing abstract concepts. When the interviewee feels comfortable with the interview process, they will be more able to handle open-ended and spontaneous questions. In comparison, non-autistic individuals are less sensitive toward open-ended questions and interview preparation.

I informed the participants at the start of each interview that it was their choice whether to speak in English or Icelandic. Our primary communication had been in English due to my foreign background. The interview frame was translated in both languages. All interviewees had an excellent command of English, so the choice of language was not a communication problem. Sometimes the women reverted to Icelandic words and phrases, which I quoted in the original language with a bracketed translation in English.

The interview process had a different flow with each participant. The interview frame was the same in general, but there were many spontaneous questions as well. For example, I did not have questions about camouflaging and life satisfaction in the initial interview frame that I emailed to the women. They started talking about those topics by their own initiative, so I decided to add those unofficial questions in the next interviews.

At the end of the interview process, I gave a clear indication when the interview was coming close to 60 minutes. Braun & Clarke (2013) give practical advice that if the researcher does not warn the interviewee that the end is near, there is a risk of losing important information when the recording has already stopped.

4.6 Data analysis

I strived to transcribe each interview and write an interpretative summary at the end of it as soon as possible, while the memory was still fresh. Each transcribed interview was approximately 30 pages, followed by another 10–15 pages with notes.

I started the process of data analysis by making a summary of each interview. In this summary, or the so-called reflective diary, I observed the process of the last interview and took notes for the next. Next, I divided the data into major groups of important information and corresponding quotes with page numbers, although not all data were directly related to the research questions. By organizing a summary of quotes in each

interview, or the so-called index card, it made writing the analysis of the entire study much easier at a later stage.

At the stage of writing descriptive commentaries, I made an initial mistake by writing them too short and too soon, which limited their interpretative potential. To rectify this, I re-wrote a more detailed version of the commentaries in the original wording of the interviewee. It proved to be a more useful practice as it preserved the rich characteristics of the individual's meaning-making. Thus, making a list of all descriptive commentaries in the latest interview served as a base for comparison with the lists of the previous interviews, and then with the next one. At this stage, I allowed myself a free flow of interpretative and conceptual ideas in the reflective diary.

At the final stage, I proceeded to the analysis of all five interviews together. I found it easier to take notes in colorful markers onto the printed documents instead of working digitally. I organized the entire list of descriptive commentaries by grouping them into clusters of main themes, subthemes, and smaller topics that were also in correspondence with each of the research questions. In this process of re-grouping and re-defining the original commentaries, they transformed gradually from descriptive into interpretative commentaries. In looking for final themes, they also became more conceptual and shorter. In the findings related to the first research question about the women's motivation for participation in the documentary, for example, the central theme was the negative impact of living without an autism diagnosis for most of their lives. The positive experience of having an autism diagnosis in their adult life was another main theme. Although it was an equally important theme, this was a relatively recent development in their lived experiences of autism. In the findings related to the second research question about the impact of participation in the documentary, two subthemes emerged: the individual's experience of the filmmaking process, and public reactions. However, because the interviews were conducted a year after the documentary was released, it was not possible to observe the long-term impact of participation.

In addition to the joint focus of participation in the documentary, each autistic woman focused on topics that were personally important to her, but there were overlapping issues of common autistic concerns because each interview was a retrospective account. Shaw (2010) wrote that the evaluation of what happened in the

past by the interviewee could change with the years, as well as during the duration of the interview as the interviewee becomes more self-aware. Initially, it was challenging to write a coherent story about the lived experiences of autistic women because I tended to adhere to the chronological order of the interviews. The result was a fragmented storyline with an emphasis on idiosyncrasies. Having a fresh memory created the problem of being overwhelmed with too many details of information. A temporary disconnection from the writing process allowed me to look at the study with a fresh perspective and keep the big picture in mind. In the final draft, I managed to focus on what the women had in common as a base, and then I added nuances of idiosyncrasies in relation to the same discussed phenomenon.

4.7 Ethical issues

In the research process, I adhered to the *Guidelines for research ethics* from the University of Iceland (2020). According to the University Ethics Committee on Scientific Research Code of Practice, perhaps I should have submitted an application to the University Ethics Committee on Scientific Research. Autistic people can be considered to be a vulnerable group because autism can present challenges in their daily lives. As all participants had openly shared their lived experiences of being autistic women in the documentary and the research focus was on their experience of participation in the documentary, my advisor and I decided that it was not imperative to submit an application to the University Ethics Committee. Furthermore, preparations for data gathering were ongoing and the committee does not review applications of studies that are works in progress.

The first important rule that I applied was the *Duty to inform participants* (University of Iceland, 2020). The interviewees received an introduction letter with the aim of the study and a written consent form prior to the interview, where they were informed about the anonymous nature of participation, the interview process, and their ethical rights. It was explained that nobody was obliged to participate and that the participant could quit the interview and the study at any point without explanation. All data were intended to be recorded, transcribed word-by-word, and destroyed no later than five years after the interview. Each consent form was signed both by the researcher and the participant.

Next, I followed the basic principle of *Respect for human dignity* (University of Iceland, 2020), which aims to protect the autonomy and privacy of participants. I used

pseudonyms and omitted any revealing personal information regarding people and places by substituting it with a related but non-specific wording in square brackets. In this way, the flow of the text was not awkwardly interrupted by a lack of context.

I was particularly mindful about the principles of *Respect for the right to privacy and intimate relationships*, *Considering the effect on third parties* and *The duty not to cause harm* (University of Iceland, 2020). In the narration of the documentary, each woman focused on an important issue for herself as an autistic individual. In their reflective accounts during the interviews, sensitive and very personal issues, which were not anticipated, were brought up occasionally. In the first subchapter of findings, for example, I applied extra caution to cause no harm to their privacy: by referring to the individual in generic terms as “a participant” and “an interviewee” in the use of sensitive and potentially identifiable quotes, and by avoiding even the use of pseudonyms. In contrast, the second and third subchapter described mostly positive feelings about having an autism diagnosis and the impact of participation, and it was a safer option to use pseudonyms freely with a few exceptions.

4.8 Self-reflection

Kristinsson (2003) highlights that researchers need to be aware of their responsibility to be honest throughout the research process because they use the trust of the participants. Taylor (1985) writes that all human beings have preconceptions and prejudices. Here, I must reflect on my personal background as a non-native Icelander, as a mother of an autistic girl, and a social educator, and how these three factors might have influenced my focus on the analysis in this study and what I did to counteract them.

Although I am not a native Icelander, I have spent 22 years, or a half of my life, in Iceland, which is why I consider myself to be a cultural insider rather than a cultural outsider in Icelandic society. As a mother, I have a firsthand experience of the social system and what services are on offer for autistic individuals. I am very satisfied with the warm and caring individual assistance that my child has received from a team of professionals since her diagnosis at the age of two. However, relying solely on experts to teach her how to lead an independent life was not a satisfactory option for me, and I felt like an outsider in her educational process by being present at meetings but without being an active force. That is why I have been on an endless journey of self-education

about autism since my daughter was diagnosed in 2008. The news of her diagnosis was presented by the experts like a permanent disability, but I was confident as a mother that the environment must be playing a big influence in her flexible future, including my efforts as a factor. My aim as a parent is not to cure autism, but to encourage my daughter's healthy self-esteem with an emphasis on her strengths, so she can enjoy a good quality of life.

In the end, I decided to become an expert myself as an insider in the service system, so I graduated with a BA in social education in 2018. I am not autistic, but learning about autism has become my greatest passion in life. The more I know about it, the more fascinating autism is as a unique and meaningful way of living. Naturally, three years was not a sufficient time to be offered a specialization in autism. When I finished my BA studies, I felt dissatisfied that I still felt like a cultural outsider to the autistic community. My negative theoretical prejudice from my BA studies was that autistic people lacked social motivation, but I knew in my heart as a mother that this was simply not true. I had a positive bias about the social skills of autistic people based on observations of my daughter, that autistic people did face social challenges but they were capable of a huge empathy, as well as a strong desire for close relationships.

In the process of this study, I realized how important autistic spaces are for autistic people for finding a sense of social belonging, and I tried to connect my daughter with other autistic friends as a result. I also registered in local and international autistic groups online because it was extremely important to hear the critical voices of autistic people about established practices and their recommendations for literature that truly reflects and respects autism. Moreover, I realized that my theoretical knowledge was mostly based on non-autistic authors prior to starting my MA in Disability Studies, which resulted in widening my perspective on autism by reading articles by autistic disability scholars.

5 Findings

In this chapter, the findings from the interviews with the five autistic women are divided into three subchapters. In the first and second subchapter, the first research question about the autistic women's motivations for participating in the documentary is addressed. It can be summarized as the importance of having an early access to autism diagnosis, especially for women. The first subchapter describes their difficult life without a diagnosis, where the following two sections explain the impact of various factors in the individual-environment fit. In the second subchapter, the five women describe their meaning-making and positive impacts of having an autism diagnosis, which are physical and mental wellbeing with a strong sense of autistic pride. The final and third subchapter answers the second research question about the impact of participation in the documentary. It is divided into two sections: about the positive and negative experiences of the filmmaking process, and the supportive public reactions.

5.1 Hardships without a diagnosis

The main motivation for participation in the documentary is increasing awareness about the benefits of having an autism diagnosis, which can be better understood in the context of having spent most of their life struggling as undiagnosed women in a non-autistic world. All five participants were late-diagnosed: one woman was in her 30s and the remaining four were older than 40 at the time of their diagnosis.

The first section explains various environmental impacts, that had formed the women's experiences of being autistic and thus their decisions to participate in the film. This includes the negative impact of sensory triggers, as well as the stress of navigating social interaction for autistic women in their daily lives. Without a diagnosis and job accommodations, they experienced a loss of job opportunities and found a solution in self-employment, partial employment and working from home. The second section focuses on their experiences of social belonging at different ages, and their relational preferences and strategies, which also affected their individual motivation to participate in the film.

5.1.1 Environmental challenges

All five women were motivated to participate in the documentary because they wanted to bring public attention to typical autistic issues, such as sensory sensitivity and the need for job accommodations. They believed that autistic people were forced into self-employment, partial employment or unemployment due to negative attitudes and lack of flexibility and adjustments.

Sensitivity to sensory stimuli, such as sounds, light and smell, was central in the accounts of the five women. In the words of one woman, they were *“a huge factor in my life and affected everything”*. Sound sensitivity includes, for example, an intolerance toward the noise from TVs and vacuum-cleaners. One woman described a strong sensitivity to visual patterns of different colors and forms in the environment, especially when she was under stress. For instance, street coating with different types of tiles was a physically uncomfortable experience which also disturbed her mental focus.

Two women had developed different ways of coping with sensory triggers. One woman forced herself to overcome her light and noise sensitivity, and reported an improvement with time in result of her efforts. In contrast, the second woman considered her pattern-thinking to be a unique talent and utilized it as a source of creativity in making patterned designs.

Furthermore, stress in the workplace is a part of environmental factors, which may trigger a self-protective response by blocking out temporarily any sensory stimuli and contact with other people. One interviewee explained that this was a response to being physically overwhelmed, but it was often misunderstood by non-autistic co-workers as a sign of self-centeredness and arrogance.

Another interviewee pointed out a need for having a very structured and predictable environment in order to reduce any sensory and stressful exposure. She also considered it as an asset in self-employment with a high reliance on self-discipline. This need, for example, was on her list of relationship issues by not getting involved with disorganized partners. She explained the value of predictability in relationships: *“Grand surprising gestures, no, I hate it. Small scale, candle-light dinner, okay, I can live with that. But throw me a surprise birthday party, I hate that.”* Another woman expressed a need for having her own room with headphones at home, and her non-autistic partner was respectful of

her autistic need for privacy. She was very appreciative of his empathy, which was the key source for her marital satisfaction.

All five women experienced some kind of sensory problems, many of which were not acknowledged by other people. This was why they were either partially employed or self-employed. One interviewee believed that autistic men got more job accommodations compared to autistic women, because of different societal expectations for men and women. Asking for accommodations did not come naturally to her. Having an autism diagnosis gave her the courage to ask for them, especially after participation in the documentary, but she expected a refusal with the excuse of financial constraints.

Another stressful factor in the environment was a difficulty with understanding and navigating social interactions. Three interviewees talked about provoking conflict situations unconsciously, because of having *“very straightforward”* personality and producing *“very embarrassing”* social situations. One interviewee compared the trauma caused by social difficulties to living with a *Post-traumatic stress disorder (PTSD)*⁵ in a constant state of perceived *“random attacks”* by non-autistic people. In general, dealing with large groups was challenging, but meeting fewer people face-to-face was not difficult. That was why all five women considered the perfect job solution for autistic people to be in self-employment and working from home.

Making social errors was described as the main reason for losing their employment, despite having good qualifications. One interviewee provided a specific example about a project, which resulted in quitting her job. The autism diagnosis made her realize that sometimes it was the situation to blame and being autistic did not make someone automatically guilty. She added: *“If I have worked on the project, I would have always regretted it. I would have felt that I have given up my beliefs.”* She emphasized her individual motivation for participation in the documentary as a contribution for improving consulting and employment services for autistic people, specifically in getting an assistance for starting their own company.

⁵ The DSM-5 criteria for PTSD includes direct or indirect exposure to a traumatic experience, which provokes the following symptoms: intrusion in daily functioning, avoidance of similar situations, negative changes in daily thoughts and mood, and hyperreactivity to stimuli.

Despite having college degrees, another woman reported that her biggest regret in life was being a wasted resource of knowledge and talents in a reduced employment due to her autistic social problems. Further, she expressed a general lack of accommodations and highlighted two aspects. Firstly, employers “*may get the wrong impression by talking to them.*” Secondly, job interviews “*are not advantageous for autistic people.*” Her main motivation for participation in the documentary was raising public awareness for the urgent need to improve recruitment and office policies on the regular job market. She clarified that job accommodations incorporated a legal right and easy availability, supportive attitude by coworkers, physical adjustment of the environment and optional training in improvement of social skills. This interviewee was very interested in learning how to improve her social skills if she was given the option by her employer because it would have been of a great help in taking advantage of her full professional potential.

The unconscious use of camouflaging as a way of overcoming social challenges was also brought up. One woman described herself as “*a chameleon*”, who had gone through life using multiple masks in different contexts. Another one said:

I have been masking for so long, that I don't know where it starts or ends. I think, I do it automatically without thinking, except when I am in a group where everyone is autistic, then I just let go.

In contrast, three interviewees expressed an inability to use, understand or relate to the concept of masking. One explained that she coped with the environment by adjusting to it and following the rules, regardless of her feelings. This woman said that she had always felt “*like an outsider and an alien.*” An alcoholic drink could help her to relax in social settings. Food had also provided her with comfort in dealing with the social stresses since her early childhood.

Without a diagnosis, the women reported a lack of explanation for their autistic social differences and, as a result, assuming self-blame instead of requesting accommodations. Consequently, difficult experiences with maintaining a good mental health was shared, which attributed to being underdiagnosed or misdiagnosed.

In summary, the environmental demands of activities in the typical work and social environments were not acknowledged and thus the women's need for adaptations, such as regarding their sensory sensitivity, were not met. Their autistic need for calm,

structured and predictable environments was highlighted as a strength of self-reliance in working from home. Navigating group dynamics was a stressful environmental factor in the individual's person-environment fit. Without an early access to autism diagnosis, the negative implications of insufficient self-awareness included traumatic social experiences, loss of employment and struggles with maintaining mental health.

5.1.2 Individual factors

The women's experiences with autistic social challenges as their motivation to participate in the documentary was affected by Individual factors, including their relational preferences and adaptive strategies.

None of the women was aware of being autistic at a younger age, when they made their educational and career-related choices. Two interviewees described having passionate interests as an autistic strength on the job market, and one found a sense of belonging in a scientific environment. She was proud when her supervisors told her that they wanted to employ more women like her. This was a pivotal moment, understanding that: *"Perhaps there is nothing wrong with me: Perhaps there is something wrong with society."* She admitted that her obsessive interests could be considered *"peculiar"* by others, because it was problematic to keep them within boundaries.

Their professional background displayed a wide range of interests and talents, but each woman explained her occupation with autism. One considered her literary profession to be a perfect fit for autistic people in the solitary occupation of freelancing. Two other claimed that the health professions and social sciences were a natural choice for autistic people, because non-judgmental attitude was a common quality in the autistic community. Furthermore, their interest in social issues was motivated by a strong desire to understand the social world.

In all five accounts, inability to handle untruth was highlighted. It was considered to be both problematic but also an admirable trait. On one hand, three women talked of having straightforward personality and the trauma of provoking conflict situations unconsciously. On the other hand, one interviewee had proudly stood up for her moral principles of justice by quitting her job.

The women explained that their social difficulties did not mean a lack of empathy. For instance, one interviewee talked of her interest in history which was motivated by a

desire to understand the nature of suffering and humanity. In her words, *“It is a big misunderstanding that autistic people don’t have empathy, we just have a different kind of empathy.”*

Additionally, an attraction toward honest and fair people, who valued integrity above all, was stressed. The quality of having a very strong sense of justice was linked with the potential of being autistic. For instance, one woman reported that some women in her feminist group realized that they were undiagnosed autistic women after watching the documentary because this attraction toward other autistic people was *“not even a conscious decision.”* Another woman claimed that *“the prejudice within the autistic community is low”* and *“we generally identify with strange people.”* In her words:

It has always interested me: people on the margin of society. I love, you know, the book characters who are usually the sorcers and witches, and the people who look at society from the outside.

Specifically, one interviewee expressed a passionate interest in organizing and maintaining autistic groups and spreading the idea of autistic spaces internationally as her main motivation. She explained that *“there is so little going on socially for autistic people”* and *“autistic people are the loneliest people on the planet.”* Next, this woman shared a comment by a happy mother: *“I managed to get him away from the computer to come here, because he was willing to meet somebody who is also autistic.”* In her experience, autistic people were not antisocial, but they simply needed the company of other autistic people to develop a sense of friendship. She clarified:

It doesn’t mean that we are better. It’s like we are tuned into a different radio station. It’s very strange, we feel some kind of a connectedness that you sense. It’s called chemistry in English.

Another interviewee also emphasized her positive experience of participation in autistic groups and spaces, because *“It was really helpful connecting with people. You know, reflect on yourself and other people: how you experience things.”* Today, all five women were active in some sort of autistic support groups and online communities which was an integral part of their emotional and social wellbeing. Despite their earlier experiences of alienation in childhood, they expressed a clear desire for belonging to other members of society.

Four women talked about a lack of connection with female peers in their playschool and school years, especially as teenagers. This included instances, when other girls were aware of their inability to understand deception and made inappropriate jokes. Such negative experiences made them skeptical of friendships later on. Consequently, two interviewees sought the company of adults in their childhood, because they offered supportive and interesting talks. One woman defended her self-esteem by being a top student, *“because then they [her peers] had to respect me”* and *“they would leave me alone and not bully me.”* At the same time, her self-protective strategy backfired because *“nobody thought that the kid with high grades, it is not possible to have a problem”* and she got no support for her social challenges.

Two interviewees simply preferred male company, because they found boys and men easier to understand. One described teen girls as her *“nemesis”*, observing that: *“If I am in a group of people, it is eight guys and me”*. The other explained that boys were more straightforward, whereas girls backtalked and were mean. In contrast, two interviewees found no gender difference in their social connectedness. For instance, one said that she had never been interested in people, and they didn't seem interested in her. Nevertheless, a recent friendship inspired a growing desire for social contact. As a senior college student, only one interviewee was lucky to find a group of female and male friends, and they were still in touch to this day. Clearly, the women displayed a varying need for social participation.

In summary, all five interviewees expressed a desire for social belonging. Regardless of their varying need for social participation, all women took part in autistic groups which provided support network and emotional wellbeing. An unconscious attraction toward honest and non-mainstream people with a strong sense of social justice, was described. The women explained their wide range of occupational choices with autism, where non-judgmental attitude, empathy and passionate interests were considered among their autistic strengths.

5.2 Benefits of the autism diagnosis

As a part of the first research question, the women's experience of having an autism diagnosis deserved a separate subchapter because it was in a stark contrast with their lives without a diagnosis. In the first section, their negative experiences with the

diagnostic services are addressed, especially the need for health professionals to be aware of the female phenotype in autism. The women's reaction to the knowledge of being autistic is also addressed. In the second section, the diagnosis provided an explanation for their autistic difficulties and the women's present state of mind is also described, as enjoying a good self-esteem, sense of autistic pride, and life satisfaction.

5.2.1 Health, safety and equality issue

The five women emphasized their primary motivation for participation in the documentary as making it easier for girls and women to get an early access to autism diagnosis. They considered this to be an equality issue, leading to improved self-knowledge, mental health and safety in relationships. The interviewees used different words as an explanation for their motivation but in the same meaning: from *“a part of feminism”* to being *“one of those invisible women, who did not even know that they were autistic.”*

Unnur emphasized the importance of getting a diagnosis for autistic individuals as an explanation for feeling different and having a peace of mind. She claimed that: *“No one should go through what I went through as a kid, not knowing”*. Anna explained that she did not know anything about autism in her youth, because *“autism was not a word, it was not an option: somehow it came into my world as a concept after 40.”* She explained that: *“It should have been obvious when I was two years old. Nobody notices it. Nobody discusses it.”* Helga made a similar observation, commenting that: *“I don't think I was invisible at all. The symptoms were already there in many ways all along, but nobody thought about autism.”*

Two women described having had an earlier mental health diagnoses which they attributed to being misdiagnosed. One embraced her autism diagnosis with a positive attitude right away because: *“I was very relieved because, you know, I already had this diagnosis of [mental health condition], so it was a great improvement of my situation.”* This interviewee described improved services after she received an autism diagnosis compared to having just a mental health diagnosis.

The other woman made a comment about her autism diagnosis compared to her mental health diagnosis: *“I don't know if someone can get a disability pension because of being autistic. If one could, I would assume that it is better being autistic than mentally*

ill.“ For her, the autism diagnosis did not include any special services and accommodations. The same interviewee observed that autism awareness had somewhat improved in the last two decades, but she believed that there were still women being misdiagnosed. She claimed that major changes were needed in society in terms of an improved autism awareness and better services.

Unnur believed that the health professionals should be informed about the gender-specific differences in autism, when women asked for a diagnosis. Hrefna had tried online tests, which were based on male criteria, but they turned out to be an insufficient information. She described a huge relief after knowing her autism diagnosis and feelings like *“climbing on top of a mountain and screaming, you know: ‘This is a thing! People have it!’”* She also compared the practical benefits of having a diagnosis to having *“an anchor.”* Another woman talked about the relief of having an autism diagnosis, because she found an explanation in autism as a neurological difference for her experience with social difficulties at the regular job market: *“So then I first understood, that I was not to blame”*.

In contrast, Anna thought that being diagnosed late in life was harder compared to being younger, because adults were more inflexible in adjusting to new situations. In her experience, *“it [self-acceptance] was a gradual thing: it was not an epiphany kind of thing”*. Her initial reaction to the diagnosis was of feeling let down, that autism was unfixable. However, her perspective had gradually changed in a similar way, that society must be fixed instead of trying to fix herself. Two women mentioned initial fears and prejudice when their autistic children were diagnosed, but their attitude had changed with self-education into a total acceptance by the time of their diagnosis.

In summary, all five interviewees were dissatisfied with the lack of autism knowledge and awareness by health professionals and society at large. They also claimed that there was a need for different diagnostic measures for autistic women. The shortage of information about autism in their younger years had resulted in internalizing the fault for their social difficulties. Although autism awareness had increased in the last decades, autistic services still needed a lot of improvement. Today, all five women accepted their autism diagnosis with a positive attitude.

5.2.2 Autistic pride and self-esteem

All five women considered being autistic as an integral part of their identity expressing a strong autistic pride and lack of desire to be cured of autism. For instance, Unnur considered her experience of being autistic as the most natural part of herself. She remembered a moment in the making of the documentary:

When [the director] asked me to tell her about my autism, I looked at her and my mind went blank. My first reaction was, yeah, to describe my autism! And I thought, how can you describe eating? How do you describe breathing? How do you describe not being autistic, because it is so ingrained into me?

She also considered herself to be *"an autistic person"* rather than a person with autism, because *"with autism"* sounded like *"with a flu"* or *"with cancer"*. In other words, *"It sounds like something, which you would like to cure. I don't agree with that kind of usage, because it is something which I definitely do not want to cure."* Helga did not either want to be cured, even if there was a treatment. She added: *"No, I am not unhappy about being autistic. I just want to be aware of it"*.

Freya explained her understanding of autism in comparison with the needs of wheelchair users, because she had always been involved with this group of people. In her words:

I don't think being in a wheelchair is a disability, because I don't think wearing spectacles is a disability. Wheelchair is just like using spectacles: you only need something to get somewhere. It's not the wheelchair, which is important. What matters is the person in the wheelchair. And it is the same with autism. Autism doesn't matter in a way: it is the person with autism who matters.

Helga defined autism in terms of ability rather than disability, because autistic people possessed many talents. Another woman talked about her rare type of a female singing voice as being autistic, which was as a metaphor for having a unique talent. Next, she added jokingly *"even the way I make my coffee is autistic"*. This last quote became the study's title, because it reflected the merging of the individual's identity with autism from the women's accounts.

In summary, the five women described autism as the most natural part of themselves, such as breathing and making coffee. They had no desire to cure autism,

because it was not an illness. They also defined it in terms of ability, such as having many and unique autistic talents, instead of a disability.

5.3 Experience and impact of participation

In this subchapter, the impact of participation in the documentary is in focus about. The subchapter is divided into two sections. In the first section, the positive and negative experiences of the filmmaking process is addressed. The second section focuses on the feedback the interviewees received from strangers after participating in the film.

5.3.1 Experiences of the filmmaking process

As aforementioned, the five women considered participation in the documentary as an opportunity for improving autism awareness in society. Unnur explained the importance of self-advocacy work: *“they [autistic people] are so used to being talked at rather than being asked. So autistic people would like to advocate for themselves and have a say.”* In her opinion, societal acceptance of autism as a natural part of life meant that public discourse should be changed into making autism more mainstream and ordinary.

Hrefna explained that during the filming the moviemakers tried to emphasize a particular autistic aspect in the participant's story, which was important to the individual herself. There was one hour and a half of preparatory interview material with each of the 17 women, and every interview was narrowed down to this chosen aspect: *“One went through diagnosis. One was talking about the Autism Café. One was talking about wanting to be a standup comedian.”* On behalf of the 17 participants, Hrefna concluded about their positive experience of taking part in the documentary, that *“90-95% are very happy with having been there.”* She explained the reason:

The word most of us use is empowerment. We feel many of us had low self-esteem and that has improved. And they feel, we all have, there is a huge gratitude, people are so thankful.

Unnur shared a commentary by another participant and her response to it: *“You do realize now that we do have become leaders?.”* And I thought, *‘Oh, fuck!’* Although Unnur defined herself as *“a reluctant leader,”* it was a display of modesty. Sharing this comment was a clear indication of their mutual satisfaction and pride with being participants.

Altogether four interviewees described their experience in positive terms, but one provided a more mixed account.

In all five accounts, the most important impact of participation was a perceived sense of kinship with the other autistic women, because of their similar experiences. In reality, the 17 women did not know each other before the filming. In the Hrefna's words: *"Okay, we felt, now I have 16 sisters that I didn't know I had."* Freya found a certain comfort in the fact, that her story was *"not unique"*. Hrefna thought that they could *"swap"* and *"mix and match"* their stories. In contrast, Anna pointed out their individual differences by saying, that *"some of their stories could have been my story but there are also quite different stories as well"*. In Hrefna's opinion, *"it [the life of autistic women] is a really big theme and so much that needs to be said."* She claimed that there was so much unused material on film, that *"they could potentially make series of the material they have."*

Furthermore, Unnur expressed a desire for continuation of the documentary in the future: *"We could have continued to make more and more material. Hopefully, we will continue making documentaries about autism."* In a potential sequel, one interviewee wanted to talk about her experience of being an autistic queer woman, for example, which the filmmakers ignored in her present story. She considered this aspect of her life to be a narrative asset, *"because that would be showing some diversity in the group"*. In her opinion, the participants in the documentary represented an incomplete image of autistic women by explaining that *"we are all white, middle-class women"*. The same interviewee made a reference to the concept of intersectionality in feminist literature, that autistic women had many interconnected identities and autism was only one of them. Two other interviewees took a similar stance by showing respect toward the LGBTQ members of the autistic community, emphasizing that autistic and non-autistic individuals had diverse identities on a wide spectrum. For the same reason, one woman refused to talk about the diagnostic criteria in binary terms of male-versus-female aspects of autism. Instead, she proposed the usage of internalized-versus-externalized categories of autism.

The interviewee, who provided a mixed account, made some critical comments about her personal experience of collaboration with the non-autistic filmmakers. She was dissatisfied with the portrayal of her story, because:

This is such a small part of my story. I am actually offended by that phrasing of my part in this film, because this is not my story. It is so much deeper and more complicated.

The preliminary interview with her was only 30 minutes, and in her opinion the directors did not *“dive into each person.”* She continued:

I guess, many of us did not have a goal about what our message should be. If she [the director] asked me this question, I would have seriously considered it. I wanted to construct something really solid, you know, but that was not the case.

She described that her trust was broken when the filmmakers ended up using a test recording that she believed what was not meant to be used. The total length and coherence of the documentary could be a potential explanation. In comparison, another interviewee claimed that although her part did not play a big role in the documentary, she was not dissatisfied in any way. However, both women were happy with the total outcome of increasing autism awareness in society.

In summary, four interviewees described their experience of the filmmaking process in very positive terms, and one woman provided a mixed account. The positive aspects of participation in the documentary included: a perceived sisterhood with the other participants, a sense of empowerment, and a desire for continuation. Two negative aspects emerged: a lack of LGBTQ representation, and a personal experience of broken rapport with the filmmakers.

5.3.2 Public reactions

Participation in the documentary included invitations for discussions about the documentary itself and various other events about autism awareness. The documentary was shown in an indie movie theater in Reykjavík in 2019 and on Icelandic National TV a year later. It is also available for rental on Vimeo with English subtitles. The interviewees described taking part in a minimum of two events in Iceland. One interviewee had been exceptionally active, both in Iceland and abroad.

Naturally, speaking in front of a camera and in a crowded space was not equally comfortable for everyone. Two women described being comfortable with public speaking, because they had been in previous leadership positions. One woman explained that she was eager to answer questions by strangers: *“So, most of the time, unless I am*

under a huge stress, I would love to answer questions and to help." She was pleased that parents had contacted her, because it was her personal mission to reduce their prejudice toward seeking a diagnosis for their children. The other woman mentioned many encounters with strangers, who praised her courage to speak about her diagnosis in public. One young woman, for example, had expressed her gratitude and said: *"My life just opened up, and I realized that I am also autistic"*. As Anna pointed out, the documentary was very useful by providing short life stories as examples for undiagnosed people.

In contrast, two interviewees expressed a discomfort with being a center of attention. Strangers had contacted one of them on Facebook, but luckily nobody stopped her in the shopping mall. She commented: *"I am rather relieved that it is not happening."* Another interviewee explained her reluctance to answer questions, because of *"performance fright and self-esteem."* She admitted that nobody had talked to her, because *"I don't know if people have not seen it [the documentary] or do not recognize me."*

At the same time, two women reported acquiring a sense of confidence by public disclosure about their diagnosis. Helga explained: *"it felt more natural to have autism and to acknowledge, and admit for other people to know that."* In Anna's experience, she had always been able to talk about autism before taking part in the documentary, but it seemed that people were not interested to listen. People only listened, because *"they don't want to be rude."* She thought that public awareness had increased in result of the documentary, because *"when it's [autism] on TV, it's concrete."*

At a relationship level, one interviewee said that the relationship with her mother had improved since the latter watched the documentary. In contrast, another interviewee experienced a negative impact from her public disclosure, when a family member was offended by her words in the documentary. She was convinced that the reaction of this person was not objective, because her words were non-specific and taken out of context.

At a professional level, one woman described herself as someone, who was not used to ask for anything. After participating in the documentary, she felt empowered to ask for job accommodations.

In summary, supportive feedback by strangers was in majority, including praise from non-autistic people, questions from parents of autistic children and gratitude from undiagnosed individuals. The documentary made it more socially acceptable to talk about their autism diagnosis and empowered them to ask for accommodations.

6 Discussion with recommendations

In this chapter, I discuss the findings in light of the theoretical coverage. In the first subchapter, I interpret the reasons for the women's late diagnosis. Next, I discuss the role of accommodations as a human rights issue, and provide suggestions based on the women's accounts. Further, a distinction is made that a provision of accommodations doesn't guarantee inclusive attitudes and two-way relationships between autistic and non-autistic people. The third subchapter focuses on the link between self-beliefs about autism and a desire to participate in self-advocacy. There, I address the importance of self-advocacy work in raising public awareness about autism, which includes two aspects: a collaboration with the filmmakers on equal terms, and the courage to be directly exposed to public attention in related events and random interactions with strangers.

6.1 Problems with the diagnostic criteria

In the final stages of analysis, the common connection appeared to be the phenomenon of being late-diagnosed autistic women, and the impact of living without a diagnosis on their experiences of autism. At first, the mature age of having an autism diagnosis seemed to be a surprising finding. On second thought, a late diagnosis made sense in the light of the fact that adult identification first became an option in the 1980s, and the widening of autism as a spectrum was recognized in the 1990s (Lai & Baron-Cohen, 2015).

In theoretical context, specific challenges exist for identifying the female phenotype in autism with a risk of misdiagnosis, because of the high frequency for co-occurring multiple diagnosis and the use of masking (Lai & Baron-Cohen, 2015). Two interviewees attributed their previous mental health diagnosis to being misdiagnosed. According to Lai & Baron-Cohen (2015), being late-diagnosed typically leads to a deterioration of mental health in more than 50% of autistic adults. Further, autistic women tend to internalize their social problems such as experiences of depression and anxiety, whereas autistic men externalize them such as a display of hyperactivity and misconduct (May et al., 2012; Oswald et al., 2016). Consequently, autistic women experience a higher frequency of mental health problems compared to men (Hartley & Sikora, 2009).

The neuroimaging study by Lai and colleagues (2018) confirms superior camouflaging strategies in women, which created the impression that all autistic women are natural

experts in masking. In fact, most interviewees said that they never used, understood, or related to the concept of masking. It is noteworthy, that those two women, who reported “chameleon” skills in their unconscious use of camouflaging in different contexts, were also the only interviewees who managed to maintain a good employment and leadership positions. This fact may explain why other people did not realize that they were autistic. According to Tierney and colleagues (2015), imitation strategies can be so effective, that other people are surprised to learn that a familiar autistic person hides their true feelings of suffering. The downside of camouflaging is that non-autistic people do not try to make accommodations for autistic needs (Crompton et al., 2020), as well as being an extremely draining effort for the autistic individual (Hull et al., 2017).

In retrospect, the interviewees claimed to have been “visibly autistic” at an early age, but nobody talked about autism. All five women mentioned an extreme sensory sensitivity to light and sounds, which must have caused a visible discomfort of being temporarily overwhelmed by blocking further stimuli and social contact. A higher frequency of sensory discomfort is, for example, a typical issue for autistic women compared to men (Lai et al., 2011).

In addition, the interviewees described a distinct disconnection from peers, especially from big groups of peers and other girls, which should have provoked a serious concern in their teachers. Bargiela and colleagues (2016) explain that the quiet, passive and compliant behavior of autistic girls is commonly encouraged by teachers as being socially acceptable according to the different gender norms in society. In particular, the interviewees identified academic success as a self-defense mechanism in protecting their self-esteem from being socially excluded. In general, they did not experience academic problems and all five women completed university education. Their retrospective accounts bring attention to two issues in mainstream schools: teachers should be mindful of autistic behavior among top female students, and social support programs should be easily available.

Another possible explanation that the social difficulties of the five interviewees were ignored by teachers was that two women expressed a preference for interactions with adults in their childhood, and two other interviewees talked about an easy connection with boys and men. Perhaps, displaying some sort of social connectedness overshadowed

their problems in interacting with female peers. This preference for male company was in line with findings by Tierney et al. (2015), that autistic women often experienced the access to non-autistic female groups as impenetrable. According to Sedgewick, Hill & Pellicano (2018), both autistic and non-autistic men focused on activities and practical aspects of friendship, which was easier to navigate compared to the emotional complexities of female relationships. However, two interviewees found no gender difference in their inability to form friendships with peers, while one interviewee was able to find both female and male friends in senior college.

In general, non-autistic children start learning social skills on the playground, but it takes a conscious and strenuous effort for autistic people (Frith, 2003). Furthermore, the communicative, cognitive and physical demands of various social activities limit the social participation of autistic children and youth (Egilson et al., 2015; Egilson et al., 2018). Thus, their social inclusion must be assisted by a collaborative effort between parents and teachers. Goodley et al. (2019) write, for example, that autism invites flexibility in the classroom organization and re-engagement of parents in the education of their children.

Participants emphasized the need for health professionals to acknowledge the existence of a female diagnostic criteria in autism. Lai & Baron-Cohen (2015) suggest that health professionals are reluctant to diagnose a woman because outdated autistic myths associate autism with severe communication problems and savant skills. All five interviewees displayed social skills in maintaining eye contact and small talk. However, they reported that failure to navigate the unwritten rules of group dynamics was a more stressful, and even traumatic, factor in the environment compared to sensory sensitivity.

Three interviewees raised the issue of respect for the autistic members in the LGBTQ community, and suggested that discussing issues with the diagnostic criteria in binary terms of male-versus-female problems was outdated. This debate about types of diagnostic categories is beyond the scope of this study. However, according to my informants the diagnostic criteria does not reflect all autistic characteristics and needs, despite inclusivity being the main intention behind widening autism as a spectrum of conditions in the 1990s.

6.2 Role of diagnosis disclosure and accommodations

All five interviewees talked about a lack of understanding and accommodations in their environment. The most important aspect of being an undiagnosed individual was the stressful navigation of social interactions due to their autistic inability to understand unwritten social rules, group dynamics and deception. In result, provoking conflict situations unintentionally often led to losing employment, which had a traumatic impact on their self-esteem and mental health. The worst consequence was assuming a personal fault. Traditionally, non-autistic people blame the fault in communication problems on the autistic individual, because the classic triad of autism theories has reinforced a public attitude toward autism as a brain dysfunction and the harmful stereotype of autistic people lacking empathy (Milton, 2012; Gernsbacher & Yergeau, 2019).

In fact, failure in communication is always a two-way street (Milton, 2012). For instance, the interviewees emphasized their non-autistic coworkers misinterpreting the temporary situations of being overwhelmed by sensory overstimulation as a rude lack of interest in communication. A study by Crompton et al. (2020) provides another example of non-autistic participants experiencing an anxiety in reading autistic states of mind by oversimplifying information in mixed interactions. Despite their good intentions to lower communicative pressure on their autistic counterparts, these authors suggested that this oversimplification had a drastic negative impact on the amount of necessary information in daily information transfer.

Receiving an autism diagnosis liberated the five interviewees from self-blame because they understood that societal awareness and attitudes about autism needed to be improved. Moreover, accommodations for special needs must be easily provided as a human right. Based on their self-reports, the need for job accommodations incorporated several other aspects: supportive attitudes by coworkers, physical adjustments of the environment and available training in social skills. Those accommodations also need to be customized, because autistic people have different personal characteristics and the nature of autism is highly individual (Davidson & Orsini, 2013). Here, it should be noted that allowing accommodations for autistic needs is not a question of preferential treatment, but an equality issue according to *The UN Convention on the Rights of Persons with Disabilities* (UN, 2006). In theory, non-autistic people should be able to recognize

the individual's autistic behavior and provide accommodations, even without an official diagnosis and a request from the individual. In reality, the interviewees reported feeling empowered to ask for accommodation by their diagnosis and participation in the documentary, but they were not used to demand anything and expected a refusal.

Asking for accommodations implies a diagnosis disclosure, but a desire for disclosure is a personal choice (Thompson-Hodgetts et al., 2020). Thompson-Hodgetts et al. (2020) reviewed recent studies about the outcomes of autism diagnosis disclosure and found that although most studies supported the positive effect of a diagnosis disclosure on social acceptance, some autistic individuals advocated non-disclosure or selective disclosure depending on the context. According to Milton & Sims (2016), there are challenges to form meaningful relationships between autistic and non-autistic people, because the latter often marginalize the autistic minority. Receiving a diagnosis often increases understanding from others, but the need to pathologize one's identity as autistic to gain support services has a negative impact on developing rapport (Milton & Sims, 2016). Even when their diagnosis is accepted, some individuals fear being treated differently and their diagnosis becoming their main public identity (Thompson-Hodgetts et al., 2020). In other words, non-autistic people still express a lesser desire for future contact, even after the disclosure improved first impressions (DeBrander et al., 2019).

However, disclosure itself is not an instruction on how to support an autistic person (Thompson-at al., 2020). Based on the five self-reports, accommodations should take into account the following autistic needs:

6.2.1 A need for calm and structured environments

As previously stated, the most common autistic feature in the female phenotype is a higher rate of sensory sensitivity compared to men (Lai et al., 2011). All five interviewees talked about sensitivity to sounds, light, smells and patterns. Stress was another type of environmental factor, which triggered a temporary mental block. Furthermore, the women reported a discomfort with crowds, as well as a preference for an organized and predictable lifestyle. They also suggested that autistic individuals are likely to flourish in an independent work from home and in self-employment, or at least in a small team of two-three people. Re-arrangement of the working environment could be another simple

solution, such as availability of a private space, headphones with noise reduction and different lightbulbs minimizing sensory triggers.

Autistic intense and persistent interests – defined as a brain abnormality in the classic autism theories – were also described by participants. This manifested as problems with multitasking and rigidity of habits (Frith, 2003). However, the same inability could be utilized as a strength of hyperfocusing on a research subject and producing an exceptionally informative and detailed report. According to Rasmussen & Pagsberg (2019), autistic people have a strong need for predictability and making agreements in advance. This is why the potential difficulty with keeping autistic interests within limitations could be easily avoided by a provision of structured and detailed instructions, which give a clear outline of expectations, responsibilities and time planning.

The interviewees explained that providing custom-made adjustments in the job environment was a legal right but not an established practise, which resulted in a high rate of autistic unemployment and a loss of their unique autistic expertise and individual talents on the job market.

6.2.2 Utilizing autistic strengths

The diverse professional background of the interviewees was an evidence for their wide range of autistic interests and talents. An interesting finding in this study was the fact, that the women linked their professional choices and hobbies with autism. Moreover, the wide range of occupations could not be narrowed down to the Theory of Autism as Extreme Male Brain (Baron-Cohen, 2002) which claims that autistic people display a preference for engineering and decreased capacity for empathizing. In contrast, four women worked in the literary, health and social professions, where empathy for human suffering was of a key importance. The theoretical explanation by Lai & Baron-Cohen (2015) about autistic affective empathy confirms the women's self-reports as having a different kind of autistic empathy. Additionally, the five interviewees described some of their best autistic qualities, such as a guaranteed authenticity, non-judgmental attitude and strong sense of social justice.

In the accounts of the five women, professional expertise and social functioning were apparently unrelated competences. The interviewees believed that autistic people could

be great employees because they had many talents. They explained that potential employers were likely to make wrong assumptions of their professional suitability, because autistic individuals experienced a high social anxiety and displayed awkwardness in face-to-face interactions. Social exclusion is reinforced by negative autism stereotypes as being awkward, difficult and angry people (Wood & Freeth, 2016). It is important for non-autistic people to understand that they must avoid making quick assumptions about the personality of autistic people as being anti-social, self-absorbed and uncaring (Gernsbacher & Yergeau, 2019). Instead of rejecting autistic individuals based on superficial first impressions (Sasson et al., 2017), non-autistic people should allow themselves to get to know each other. The study by Morisson et al. (2019) showed that the quality of interaction did not differ for non-autistic and autistic partners, meaning that autistic people were not judged as less intelligent and less trustworthy by both groups. Lai & Baron-Cohen (2015) propose that non-autistic people must show appreciation for their autistic knowledge in the experience of shared interests in order to make the autistic individual feel welcome and relaxed in mixed interactions.

A specific reason for the potential unemployment of autistic individuals was, for example, that the job interviews were not advantageous for them. According to Parsons et al. (2019), job interviews would become more suitable in computerized testing, because autistic people experience more control over interactions and reduction of anxiety via technology instead of face-to-face communication. In comparison with those autistic candidates, who work in the care-taking professions with a high demand for face-to-face interactions, their applications must not be dismissed and discriminated based on the negative stereotype of autistic people lacking empathy (Holt et al., 2021). Instead, they should be given the chance to be interviewed and evaluated on individual basis, because the nature of autism is highly individual (Davidson & Orsini, 2013).

6.2.3 Support for two-way relationships

The five interviewees expressed a clear desire for social belonging, although they preferred social interactions to a varying degree. Tierney et al. (2015) write that autistic girls and women have a great motivation to form friendships, but finding them is not easy. As a positive consequence of receiving a diagnosis, all five women reported the joy of finding a sense of belonging in autistic communities because autistic people had a natural

“chemistry” bonding easily with each other. Although this was a positive development in their social life, it was also an indication of non-inclusive attitudes in mainstream settings.

In other words, autistic social motivation is not an individual but a relational outcome depending on the person-environment fit (Morrison et al., 2019). According to Crompton, Hallett et al. (2020), meaningful two-way relationships between autistic and non-autistic people are possible despite differences of communication style and being a rarity. Lai & Baron-Cohen (2015) suggest that non-autistic people must be proactive in integrating the autistic individual into group activities. In particular, the authors propose the inclusion of autistic people in highly structured activities, such as card games. The help of non-autistic friends is also invaluable in explaining group dynamics and the wider context of events (Crompton, Hallett et al., 2020).

In summary, provision of accommodations and social inclusion were interconnected but also separate issues in the women’s self-advocacy for equality. Removal of environmental barriers by law does not automatically guarantee a lack of prejudice and social inclusion because relationships with non-autistic people are likely to be still challenging (Milton & Sims, 2016). In other words, inclusion is a two-way desire for connectedness in line with the Double Empathy Theory (Milton, 2012).

6.3 Role of autistic identity and self-advocacy

The five women displayed a positive attitude toward autism with a sense of life satisfaction today. Their responses indicate an autistic pride and a lack of desire to be cured of autism. The individual’s belief about autism has an important impact on their self-esteem and mental well-being, which is often molded subconsciously by the social norms of ability and disability as internalized oppression (Goodley et al., 2019). For instance, language management is a form of empowerment by reframing the deficiency discourse in the biomedical model into a positive new identity (Shakespeare, 2014). In this study, the five women supported the use of identity-first language, or autistic people. Furthermore, they explained autism as a natural part of themselves, like breathing and making coffee, and used it as a metaphor for having unique talents.

A unique finding in this study was the definition of a shared attraction toward honest, fair and non-conformist people, who are often autistic. The likelihood of being attracted

toward other autistic people unconsciously is in line with the Double Empathy Theory (Milton, 2012). Several studies support this theory, that autistic people feel more socially confident with other autistic people (Gernsbacher et al., 2017), tend to disclose more personal details to each other (Morrison et al., 2019), and find autistic spaces to be very comforting (Crompton et al., 2020). At the same time, those honest and non-mainstream people may not be autistic, which is an interesting aspect of the same finding.

In other words, the practical and positive impact of supporting the autistic diagnostic label and the neurodiversity concept is undeniable in terms of the individual's self-acceptance, as well as finding a sense of belonging in the autistic community. However, I see the concept of neurodiversity as a transitory step toward an inclusive society, because the problem with the global politics of diagnosis is the grouping of people in terms of the same and others, as pointed by Goodley (2018). If the world was respectful toward human diversity, diagnostic labels would not be needed.

As a result of the documentary, the interviewees experienced an empowerment because it seemed to be more socially acceptable to talk openly about being an autistic person. The interviewees reported receiving only positive feedback of encouragement by strangers. This feedback included questions from parents of autistic children, gratitude from undiagnosed individuals, and praise from non-autistic people.

At a personal level, two interviewees reported a mixed impact of participation in the documentary on their relationship with family members: as a positive consequence of improved understanding and connectedness in the first case, and as a negative one of generic comments being taken personally in the second case.

The most positive experience of participation in the filmmaking process was the discovery of a sisterhood by the five interviewees with the other participants, because of their shared experiences as autistic women. One interviewee talked about broken rapport with the non-autistic filmmakers. Her comments made me re-think my own responsibility as a non-autistic researcher, that I should be wary of not misinterpreting autistic culture by using my own non-autistic agenda and biases from the position of academic power. Similar aspects have been raised by autistic scholars (Cascio et al., 2020; Chown et al., 2017; Parsons et al., 2020).

7 Conclusion

The five women participated as self-advocates in the documentary to raise societal awareness about the important access to an early autism diagnosis in terms of self-acceptance, reduction of social difficulties and improvement of daily and professional functioning. In general, adult autistic women tend to be underdiagnosed and misdiagnosed for many reasons; for example, a lack of available information about the female type of autism, other co-occurring diagnosis, and their potential use of masking. The five women highlighted the major consequence of living without a diagnosis was internalizing the fault for their social difficulties, which had a negative impact on their self-esteem and mental health.

If autism awareness was increased in society, non-autistic people would be able to recognize autistic behavior and provide support services and job accommodations, even without an official diagnosis and a request from the individual. Allowing accommodations for autistic needs is not a question of preferential treatment, but an equality issue according to *The UN Convention on the Rights of Persons with Disabilities* from 2006.

The most important experience of participation in the documentary was the discovery of a sisterhood by the five interviewee with the other participants, because of their shared experiences as autistic women. Although necessary, their diagnosis disclosure was, however, not enough for societal inclusion.

Social inclusion and provision of accommodations are interconnected but also separate issues in the autistic self-advocacy for equality. Meaningful relationships with non-autistic people are possible, if they show willingness to listen and learn about the autistic perspective of social interactions. The existence of autistic spaces and self-advocacy is extremely helpful, but they will not be necessary in an inclusive world. The creation of this documentary by non-autistic filmmakers, and the emphasis on participatory research in the future are two examples of a willingness for collaboration with autistic people in the co-creation of autism knowledge.



Kremena Nikolova-Fontaine

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Appendix A – Letter of intent to conduct research

Fylgiskjal nr.

[dag...] [mán..] 2020

Reynsla einhverfra kvenna af þátttöku í heimildarmyndinni *Að sjá hið ósýnilega*

Ábyrgðarmaður rannsóknar: Snæfríður Þóra Egilson, prófessor við Félagsfræði-, mannfræði- og þjóðfræðideild Háskóla Íslands, netfang: sne@hi.is , sími: 525-4264.

Kæri viðtakandi,

Ástæða þessa bréfs er að óska eftir þátttöku þinni í rannsókninni *Reynsla einhverfra kvenna af þátttöku í heimildarmyndinni Að sjá hið ósýnilega*. Rannsóknin er hluti af meistararitgerð Kremena Nikolova-Fontaine, þroskaþjálfara, nema í fötlunarfræðum við Félagsfræði-, mannfræði- og þjóðfræðideild Háskóla Íslands sem jafnframt er móðir einhverfrar stúlku á unglingsaldri.

Kveikjan að rannsókninni var heimildamyndin *Að sjá hið ósýnilega* [Seeing the Unseen] (Bjarney Lúðvíksdóttir og Kristján Kristjánsson, 2019). Þetta er í fyrsta skipti bæði héraendis og erlendis sem heimildarmynd fjallar um einhverfar konur á fullorðinsaldri. Heimildarmyndin vakti mikla athygli og varð til þess að rannsakandi ákvað að beina sjónum að þeim áhrifum sem þátttaka í heimildarmyndinni hafði á nokkrar af þeim konum sem þar komu fram.

Markmið rannsóknarinnar er að draga fram reynslu kvennanna af þátttöku í heimildarmyndinni *Að sjá hið ósýnilega*. Jafnframt að kanna hvort og þá hvernig þátttaka

í heimildarmyndinni hafði áhrif á sjálfsmynd þeirra, skilning þeirra á einhverfu sem og viðhorf almennings til einhverfugreiningar.

Í rannsókninni verður leitast við að ná til fimm kvenna með einhverfugreiningu yfir 18 aldri sem voru líka viðmælendur í heimildarmyndinni *Að sjá hið ósýnilega*. Þær hafa fengið dýrmæta reynslu af því að fræða almennings um einhverfu.

Hlutverk þátttakenda er að koma í eitt viðtal sem áætlað er að taki um eina klukkustund. Þátttakandi velur stund og stað fyrir viðtalið. Viðtal við þátttakanda verður hljóðritað og afritað orðrétt. Farið verður með allar persónuupplýsingar og skráningu þeirra í samræmi við lög um persónuvernd og meðferð persónuupplýsinga. 100% trúnaðar verður gætt gagnvart öllum þátttakendum.

Öll gögn er tengjast rannsókninni verða varðveitt á öruggum stað á meðan á rannsókn stendur og verður þeim eytt að rannsókn lokinni eigi síðar en fimm árum eftir rannsóknarlök, í votta viðurvist.

Áréttað skal að þér ber ekki skylda til að taka þátt í þessari rannsókn og þú getur hætt við þátttöku hvenær sem er, án nokkurs fyrirvara eða útskýringa.

Virðingarfyllst,



Kremena Nikolova-Fontaine, þroskaþjálfari og M.A. nemi í fötlunarfræðum við Félagsfræði-, mannfræði- og þjóðfræðideild Háskóla Íslands,
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Appendix B – Letter of introduction and informed consent

Fylgiskjal nr. 1

Samþykkisyfirlýsing vegna rannsóknarinnar: Reynsla einhverfra kvenna af þátttöku í heimildarmyndinni *Að sjá hið ósýnilega*

Ég undirrituð samþykki hér með að taka þátt í rannsókninni *Reynsla einhverfra kvenna af þátttöku í heimildarmyndinni Að sjá hið ósýnilega* eins og henni er lýst í kynningarbréfi og svara spurningum um reynslu mína af þátttöku í heimildarmyndinni.

Þátttaka felur það í sér að fara í eitt viðtal hjá rannsakanda. Viðtalið mun taka u.þ.b. eina klukkustund. Viðtalið verður tekið upp og síðan afritað.

Allar þær upplýsingar sem ég gef í viðtalinu verður farið með sem trúnaðarmál. Farið verður með öll gögn rannsóknarinnar samkvæmt lögum og reglum um vísindarannsóknir og öllum frumgögnum verður eytt að rannsókn lokinni í votta viðurvist, eigi síðar en fimm árum eftir að rannsókn lýkur.

Mér er ljóst að ég get hætt þátttöku á hvaða stigi rannsóknarinnar sem er, án frekari skýringa.

Dagsetning

Undirskrift viðmælanda

Ég staðfesti hér með að hafa veitt þátttakanda upplýsingar um eðli og tilgang rannsóknarinnar.

30.nóv.2020



Dagsetning

Undirskrift rannsakanda

Appendix C – Interview frame

The experience of autistic women participating in
the documentary *Seeing the Unseen*

(f. Reynsla einhverfra kvenna af þátttöku í heimildarmyndinni *Að sjá hið ósýnilega*)

Takk kærlega fyrir að samþykkja að taka þátt í þessu viðtali um reynslu einhverfa kvenna af þátttöku í heimildarmyndinni *Að sjá hið ósýnilega*. Rannsóknin verður skrifuð á ensku en þú ræður sjálf hvort vilt þú þig á íslensku eða á ensku. Er þægilegra fyrir þig að tala á íslensku eða á ensku? Thank you for agreeing to take part in this interview about the experience of autistic women participating in the documentary *Seeing the Unseen*. The research will be written in English, but you can decide whether you want to speak in Icelandic or English. Is it more convenient for you to speak in Icelandic or English?

I. Almennar upplýsingar/ General information

1. Ég ætli byrja með spurning með almennum upplýsingum um bakgrunn þín. Hvað getur þú sagt mér frá sjálfri þér (til dæmis, aldur, búseta, fjölskylduaðstæður, menntun eða starfsreynsla)? I will start with a general question about your background. What can you tell me about yourself, for example, your age, location, family situation, education, and work experience?

2. Hvernig getur þú lýst sjálfri þig sem manneskja? Hvað eru þínir styrkleikar, til dæmis sem fjölskyldumeðlimur, vinkona eða starfsmaður? How would you describe yourself as a person? What are your strengths, for example, as a family member, a friend, or an employee?

II. Þátttaka í heimildarmyndinni/ Participation in the documentary

4. Getur þú sagt mér um reynslan þína af þátttöku i heimildarmyndinni *Að sjá hið ósýnilega*? Can you tell me about your experience of participating in the documentary *Seeing the Unseen*?

- *Af hverju tókst þátt í myndinni? Hvað var megin skilaboðið þitt til almennings?*
Why did you decide to participate in the film? What was the main message you wanted to convey to the public?
- *Hvað voru væntingar þínir? What were your expectations?*
- *Voru einhverjar efasemdir til staðar? Did you have any reservations?*
- *Var eitthvað jákvætt af þátttöku þinni i heimildarmyndinni? Was there anything positive about your experience participating in the documentary?*
- *Var eitthvað neikvætt af þátttöku þinni i heimildarmyndinni? Was there anything negative about your experience participating in the documentary?*
- *Ertu sátt við útkomuna? Nærðu að fjalla um öllu mikilvægustu atriði sem þú vildi tala um? Are satisfied with the outcome? Did you manage to talk about the most important things that you wanted to talk about?*
- *Hafði gerð heimildarmyndarinnar einhver áhrif á sjálfsmynd þína og skilningin á einhverfu: a) meðan á henni stóð og b) eftir? Did the making of the film have any impact on your identity and understanding of autism a) while it was being made, and b) afterward?*
- *Hver eru viðbrögð annarra við heimildarmyndin? Sem dæmi, færðu meiri skilning og stuðning frá fjölskyldumeðlimum, vinum og fólkinu í nánasta umhverfinu? How have people in your life responded to the documentary? For example, do you get more understanding and support from family members, friends, and others in your immediate surroundings?*
- *Ræðir ókunnuglegt fólk myndina við þig? Ef já, finnst þér athyglin þægileg eða óþægileg? Do strangers discuss the film with you? If yes, are you comfortable or uncomfortable with the attention?*

- *Finnst þér að hefur orðið vör við einhverjar breytingar í samfélaginu eftir að heimildarmyndin var sýnd? Ef nei, hvers konar breytingar eru nauðsynlegar á þjónustu fyrir einhverft fólk og viðhorf almennings á einhverfu?* Have you noticed any changes in society following the premiere of the film? If no, what kind of changes are necessary in relation to services provided for autistic people and in terms of public attitudes?
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III. Einhverfa/ Autism

Þú veist, ástæðan að bjóða þér í viðtal er að þú varst hugrökk að fjalla opinbera um hvað þetta þýðir fyrir þig að vera einhverf kona. Reynslan þín að fræða almennings um einhverfu er mjög dýrmætt af því að það er skortur af rannsóknum um líf einhverfra kvenna. You know, the reason I invited you for an interview is that you have been courageous about speaking in public about what it means to you to be an autistic woman. Your experience in educating the public about autism is invaluable because there is very little research written about the lives of autistic women.

5. Hvað þýðir að vera einhverf fyrir þig? What does it mean to you to be autistic?

- *Hvaða gömul varstu þegar þú fékk greininguna?* How old were you when you were diagnosed?
 - *Þegar þú lýsir sjálfan sig sem manneskja, er einhverfa helstu atriði í lýsingunni eða þetta er ein af mörgum persónueiginleikum?* If you were to describe yourself as a person, would you say that autism is one of your most important characteristics or just one of many aspects of who you are?
 - *Skiptir það máli fyrir þig hvort þú ert „einstaklingur með einhverfu“ eða „einhverfur einstaklingur“?* Does it matter to you whether you are described as "a person with autism" or "an autistic person"?
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IV. Einhverfukaffið / The social gathering called The Autistic Coffee

Heimildarmyndin fjallaði um Einhverfukaffið þar sem einhverft fólk hittast reglulega, og konurnar hafði lýst ánægju sína að tengjast öðrum einhverfurófi. Allir 17 konur, sem voru þátttakendur í heimildarmyndinni, þær voru líka virkir að mætta á Einhverfukaffið. The documentary discussed The Autistic Coffee, where autistic people meet regularly, and the women expressed satisfaction about connecting with other people on the spectrum. All 17 women who participated in the documentary were also active in attending The Autistic Coffee.

6. Getur þú sagð mér meira um Einhverfukaffið og samskipti við einhverft fólk? Can you tell me more about The Autistic Coffee and interactions with other autistic people?

- *Hafur þú kynnst þessar aðrar konur áður en þið tóku þátt í heimildarmyndinni? Hafi það orðið til vináttusambönd við gerð heimildarmyndarinnar?* Did you know any of the other women before taking part in the documentary? Have any friendships formed in the process of participating in the documentary?
- *Hvers konar hlutverk hefur Einhverfukaffið á líf þitt?* What kind of role does The Autistic Coffee play in your life?

V. Lokaspurningar/ Final questions

- *Ertu ánægð með viðtalið? Viltu bættu einhverju við?* Are you happy with the interview? Is there anything else you want to add?
- *Má ég hafa samband við þig aftur ef eitthvað er óskýrt?* May I be in contact with you again if something is unclear?